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ABSTRACT

The status of early intervention programs for handicapped young children in New Jersey is examined through analysis of results from a parent questionnaire, program administrator survey, functional assessment forms on children, group interviews with staff and parents, and phone interviews with program administrators. Among results reported are that the programs serve a relatively wide cross section of the general population; socioeconomic status does not appear to be very influential in a parent's selection or a child's referral to a particular program type; it appears that a number of children needing services are not enrolled in early intervention; a number of procedures are used to ensure program quality, but few standardized monitoring and evaluation programs exist; overall, parents and staff share similar views of a child's functioning, particularly in gross motor skills; and parents' predictions about the child's functional capabilities at the age of 3 are similar to the staff's. (CL)

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A STUDY OF EARLY INTERVENTION PROGRAMS IN NEW JERSEY

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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SUMMARY

In recent years, the New Jersey Developmental Disabilities Council has encouraged the growth of early intervention programs throughout the state. The programs are designed to provide assistance to children (age 0-3) with developmental disabilities and to their parents. In the fall of 1978, the Council asked the Developmental Disabilities Training and Technical Resource Center, a federally funded technical assistance project, to conduct an extensive review of early intervention programs and collect data on a number of specific issues. The primary purpose of the study was to describe the programs with respect to certain characteristics and to assess consumer satisfaction. A number of different methods were used to gather data. Each program associated with the New Jersey Coalition of Infant Program Administrators received a packet of data collection instruments. Programs mailed eligible parents a questionnaire. Administrators completed a survey instrument describing various aspects of their program. Staff members provided a functional description of each child by filling out a "Functional Assessment Form" derived from the Denver Developmental Screening Test. In separate meetings, group interviews with parents and staff were held to collect additional information about program strengths and weaknesses.

The findings are summarized as follows:

- Services are being provided to children from a broad spectrum of families with respect to such demographic factors as age, socioeconomic status, education.
- Programs are located in a variety of settings. No one type of setting predominates.
- Programs receive funding from different sources. Only two programs receive all their income from one source. Of those who receive Council funding, this assistance represents the largest proportion of their income.
- Based on prevalence rates and service capacity, it is reasonable to assume that there are a number of children in New Jersey who need early intervention services but are not receiving them. One reason for this gap may be that parents have a relatively difficult time learning about the existence of programs.
- Despite many different strategies used by programs to publicize their existence, more remains to be done, particularly in communicating to the medical community that early intervention programs represent a viable treatment alternative.
- Nearly all programs have an individual habilitation plan (IHP) for each child; however, they differ greatly with respect to what information is included on this form.
- Overall, parents were highly satisfied with most aspects of the programs. Both staff and parents provided details on what they considered to be actual accomplishments of the programs.
- Benefits were reported not only for the children but also for the parents, their marriages, other siblings, and the community at large.
- Parents and staff appeared to have similar views with respect to a child's expected functional capabilities.
- Most centers consider parent participation in the child's treatment at the center to be of primary importance. While programs typically offer many forms of parent participation, there appeared to be disagreement among parents regarding which forms of parent participation existed in their particular center.
- Parents appear to prefer a more active role in the child's treatment at the center.
- Transportation difficulties were a concern of many parents and staff. In some cases, parents could not enroll their child if programs did not provide transportation.

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1.0 BACKGROUND OF THE STUDY

1.1 Purpose

There are approximately thirty programs in the State of New Jersey that provide early intervention services to infants (age 0-3) with developmental disabilities. Typically, these programs attempt to aid child development through parent training and direct therapy with infants. Services are provided either in a particular treatment center or in the parents' home. The programs vary in structure, design, and organizational affiliation. When viewed as a group, the early intervention programs exhibit no uniform standards or proven methods. Rather, each program appears to be unique.

At the request of the New Jersey Developmental Disabilities Council, the Developmental Disabilities Training and Technical Resource Center (DDTRC) of Welfare Research, Incorporated (WRI) undertook the task of assessing early intervention programs throughout the state. The specific goals of the study were as follows:

- To clarify important aspects of early intervention programs by describing commonalities and differences among the programs in New Jersey
- To determine the extent of parent satisfaction with these programs and explore factors that might influence the level of parent satisfaction

To address these goals, the DDTRC focused on the following aspects of each program:

- population being served
- forms of parent participation
- functional capabilities of children
- perceptions of parents and staff regarding program strengths and areas for improvement

1.2 Background of the Study

During the last decade, services to infants with developmental disabilities have been greatly expanded by the rapid growth of early intervention programs. The New Jersey Developmental Disabilities Council has played an important role in this expansion by providing funds to develop new programs and to improve existing services. For Fiscal Year 1980, the Council determined that early intervention programs would be one of its two priority areas.

In November 1978, the DDTRC, which provides training and technical assistance to Developmental Disabilities Councils in HEW Region II, was asked by the New Jersey Council to become involved in an evaluation of infant programs. The Council, acting on recommendation of its Program Monitoring Committee, determined that an investigation of early intervention programs in the state would be useful and consistent with the priorities set forth in the FY 1980 State Plan. In April 1979, DDTRC staff met with the Executive Committee of the New Jersey Council and identified the major issues to be addressed by the study.

1.3 Issues Addressed

During the formulation of the study, the major concern of the New Jersey Developmental Disabilities Council was the examination of the status of early intervention programs in the state. In essence, the Council wanted to assist the impact of its previous years of support. In order to focus on the Council's most pressing areas of interest, a list of specific questions was generated by the Executive Committee (Table 1).

As the research plan was developed, the Council's questions were modified and grouped into four categories (Table 2). The only substantive change made in the course of planning was related to the issue of "realistic expectations" (question 11); realizing that it would be very difficult to determine objectively whether a parent's expectations were indeed "realistic," the Executive Committee and DDTRC staff agreed that on this issue the study would be limited to an assessment of congruence between staff and parent views regarding the child's functional capabilities.

Table 1. Original Questions Posed by Executive Committee

1. Sociological analysis of the population served by early intervention programs:
   - Which children are receiving SSI?
   - Which children are in Department of Health programs?
2. What efforts are made to reach the population? How did parents first hear about the programs?
3. How soon after diagnosis is the referral being made? By whom?
4. What is the frequency of re-evaluation of a child?
5. What are the settings and major funding sources of programs?
6. To what degree are the number and location of programs meeting existing demands for services?
7. What is the mix of functional impairments across all programs and within particular program models?
8. How does the program model (including the philosophical model) correlate with other issues previously identified?
9. How does the diagnostic label affect participation? What are the functional limitations vis-a-vis the diagnosis?
10. What are the transportation problems (time, money, etc.)?
11. What measures of parent satisfaction do we find? Were the parents realistic? What were their expectations?
12. What are the results as perceived by parents and professionals?
13. What are the monitoring and evaluation processes of the programs?

In identifying specific issues, the Executive Committee realized that certain questions could not be addressed within the scope and resources of the present effort. They included the following:

- What was the improvement for the parent or child?
- What are the linkages between infant programs, hospitals, and agencies?
- Is the program effective for next steps? Is there a next step?
- Are there any alternatives to infant stimulation programs?
- Are we duplicating services already available?
- Are improvements lasting?
- Are alternatives available to parents who are unwilling/unable to participate?
- Are programs cost effective? What is the cost per child?
- What are the attitudes of professionals towards parents? How do they relate to parents and vice versa?
- What is the education/awareness level of the medical profession regarding early intervention programs?

Based on the findings presented herein the Council will hopefully be in a better position to take additional steps to address these and other important issues related to early intervention programs in New Jersey.

Table 2. Revised Questions Developed for the Study

I. **Characteristics of Population Being Served**
   A. What are the family backgrounds of people being served by programs?
   B. What are the functional capabilities of children across all programs?

II. **Enrollment in Programs**
   A. How well are centers meeting the existing demand for services?
   B. How did parents first hear about the programs?
   C. What are the key issues related to a child's referral to a program?
   D. How do programs communicate their existence?
   E. What are the events and dynamics surrounding the intake process?
   F. What are the physical settings of programs?
   G. What transportation problems are noted?

III. **Characteristics of Programs**
   A. What are the major funding sources?
   B. What are the monitoring and evaluation processes of programs?
   C. To what degree do various program models display distinguishing features?
   D. To what degree do the functional capabilities of infants vary across program models?
   E. What is the relationship between parent and staff assessment of the child's functional capabilities?
   F. To what degree does a categorical diagnosis describe functional capabilities?
   G. How does a categorical diagnosis affect participation in programs?
   H. How often do programs re-evaluate children?

IV. **Perceived Outcomes of Programs**
   A. What patterns are seen in parent satisfaction?
   B. What do the programs accomplish, as perceived by the parents and staff?
   C. What are the improvements in programs, as perceived by parents and staff?
   D. How does the future of the child appear to parents?

2.0 LITERATURE REVIEW

2.1 Overview

Despite the extensive body of research on early intervention, major problems exist in drawing definitive conclusions from what has been written. For several reasons, described below, it is difficult to generalize findings from the existing literature to the early intervention programs described in this report.

Much of the literature refers to different populations from those addressed by this study. The ages of children described are often over the 0-3 range, so that, in effect, preschool programs and not early intervention programs are being examined. Also, much of the research has been conducted with "disadvantaged" children as opposed to "developmentally disabled" children. For example, the most extensive review to date of the effectiveness of early intervention (Bronfenbrenner, 1975) refers mainly to studies of disadvantaged children.

Another problem is a lack of precision in many of the studies, which makes it difficult to establish point-by-point comparisons. For example, rather than explaining the features that are implied by the phrase "early intervention", many of the studies assume that programs are homogenous with respect to frequency of meeting, structure, and other characteristics. Often the actual "intervention" offered is not described. In methodology, the studies include a variety of outcome measures, which makes comparisons among programs difficult. Moreover, because many of the studies used no control group, it is also difficult to make inferences about program effectiveness.

The salient conclusion emerging from these limitations is not that related research is of little value but, rather, that careful judgements need to be made regarding the application of findings to the early intervention programs described in the report.

2.2 Effectiveness of Early Intervention

Few investigators have provided documented evidence to support the conclusion that intervening early in the life of a child can make a **lasting** difference on life-long development. Most research focuses on the analysis of short-range results. One exception is Skeeles (1966), who conducted a follow-up study on mentally retarded children who were institutionalized in the 1930's. The experimental group were given stimulation by mother-surrogates, also mentally retarded, while a control group remained in an orphanage setting. In the follow-up study, conducted when the subjects had reached an adult age, dramatic differences in these two groups were seen with respect to place of residence, educational attainment, occupational status, and marital status. Members of the experimental group were leading a much more "normalized" existence.

While initial evaluations were not promising, recent analyses of the long-term benefits of Head Start programs (Lazar & Darlington, 1978) have also pointed to the value of intervening early in the life of a child. Head Start experiences appear to lead to such results as students' being proud of themselves for reasons related to higher achievements, and less grade retention. In addition, mothers whose children were in Head Start programs had higher vocational aspirations than non-Head Start mothers.

A number of studies have concentrated on documenting the more immediate benefits of early intervention. Some research has focused on child progress (Levenstein, 1970; Ramey & Smith, 1977; Scarr-Salapetek & Williams, 1973) as the outcome variable. In one study, four out of seven infants with delayed motor development before the age of 1 year were normal at the age of 3 (Solomons, Holden, & Denhoff, 1963).

The benefits of early intervention can include the parents as well as the children. Meisel (1976) evaluated a national collaborative project of early intervention programs for handicapped infants. Data seemed to support the conclusion that progress was made by children with Down's Syndrome due to program intervention. Parents reported a greater ability to manage their child at home and a greater persistence in helping their child. While another study indicated that low-functioning children did not make significant advancement, attitudinal changes in parents warranted the child's participation; parent attitude change was not found to be related to the child's functional level (Gordon, Gitter, Schwartz, Exrachi, Brenner, Bives, & Diller, 1975).

Some studies are not so conclusive in supporting the benefits accrued by an early intervention experience. In one study, although initial gains were positive, children showed a drop-off in developmental progress when they entered the elementary grades (Hilgard, Jones, Waldemar, Toczek, & Barrett, 1962; McGraw, 1939; Schaefer & Aaronson, 1972). In another study, early intervention produced the predicted change (i.e., in those developmental areas where intervention was concentrated) in four of the seven children. However, two children showed no real response to intervention, while one demonstrated a developmental pattern opposite of what was expected (Barrera, Routh, Parr, Johnson, Arendshortt, Goolsby, & Schroeder, 1976). One investigator attempted to explain the individual variation among children by hypothesizing that developmental progress resulting from early intervention is a function of the amount of organic damage in infants with biological impairments; in general, progress was inversely related to the degree of cognitive deficits (Brassell, 1977).

2.3 Age of Child When Enrolled

One question pursued by many investigators is whether there is an optimal program entry age for children. Some suggest that the earlier a child enrolls, the better (Kong, 1966; Levenstein, 1970; Sequin, 1966). Children are considered to be in their most "plastic" state when they are under 5, and in those early years, presumably, 50 percent of all growth in intelligence takes place (Bloom, 1964). However, others maintain that child development is too complex an event to simply assert that earlier enrollment in a program will always produce the best results (Caldwell & Richmond, 1968; Magill, 1976). One review of research implies that developmental gains are more a function of what the program **does** with the child than of entry age (Stedman, Anastasiow, Dokecki, Gordon, & Parker, 1972).

2.4 Important Program Characteristics

Researchers have attempted to describe various aspects of programs that are critical for successful outcomes. One of the most often cited characteristics is the maintenance of the special role played by parents. Some would argue that parents need to be the primary treatment provider (Conner, Williamson, & Siepp, 1978; Lapidakis, 1976; Moersch & Wilson, 1976). Others imply that parents should be central participants in the intervention process (Bronfenbrenner, 1975; Meisel, 1976). However, differences in how authors describe parent participation in the treatment process may be semantic; there seems to be agreement that parents need to be maintained as the primary caretaker of the child. One author, in fact, suggests that if early intervention programs separate the parent and child, more harm than good may emerge (Lacoste, 1978). Another asserts that programs may need to be more creative and persistent in their efforts to maximize parent participation through such methods as involvement in agency administration and the development of a unified community interagency referral policy (Rosen, 1978).

Where the intervention takes place (center, home, school) is another salient feature of the programs (Goldberg & Wolk, 1976).

With respect to staffing patterns, one model early intervention program describes the primary staff as occupational, physical, and speech therapists, with a special educator and psychologist functioning as secondary staff (Moersch & Wilson, 1976). These positions are often associated with the transdisciplinary approach. By this approach, in order to avoid overstimulation of the children by interaction with many different staff members, one staff member is given primary responsibility for each child (Conner, Williamson, & Siepp, 1978). Staff members incorporate skills from fields other than their own and thus "extend" the role typically ascribed to their particular profession.

Little has been written detailing what actually takes place within programs. Conner, Williamson, and Siepp (1978) attempt to describe modes of service delivery; for example, some programs are focused on the individual child while other programs may provide treatment in group setting. Some researchers see a tendency toward informality and contend that more rigorous and carefully designed programs are needed (Levitt & Cohen, 1975). These researchers were unable to discern patterns among those programs with successful outcomes. Others have had difficulty labeling program models and maintain that the development of variables describing successful program models is a task yet to be accomplished (Ackerman &

Moore, 1976). According to one researcher (Sigel, 1972) programs would improve in effectiveness if they gave more thought to developmental theory when planning their daily sessions.

Two reports attempt to outline early intervention networks within a particular geographic region. In a study of programs in Minnesota, Goldberg and Wolk (1976) examined all early childhood programs, including nursery schools.

It was found that 1,102 handicapped children (0-5 years old) were being served, but with relatively few in the under-3 age bracket; as of 1975, nine programs concentrated on the under-3 group. The most frequently cited diagnosis was developmental delay (40%). Approximately one-third of the children were characterized as "poor", with 15.6% of the total from minority backgrounds. In another report, which looked at programs in a section of Texas (Macy Research Associates, 1978), the age range and developmental abilities of the children studied were more closely related to those in the New Jersey programs. The average age of the children was 21 months, and 47% were from minority backgrounds. The primary handicapping condition most often noted was mental retardation (29%), with developmental delay a close second. Overall, parents were quite satisfied with programs. They were least satisfied in the area of "helpfulness to the family."

2.5 Administrative Issues

The lack of central government coordination and support of early intervention programs is a problem cited by many investigators. Stedman et al. (1972) express concern over the lack of a "central governance and nurturance system" that could coordinate various research efforts. One study suggests that commitment and collaboration on a national level might help in exploring the effectiveness and efficiency of programs (Simeonson & Wiegerlink, 1975). Ackerman and Moore (1976) contend that the large number of children in need of services but not being served reflects the fact that federal mandates do not require states to serve children under 3 with handicaps. Also, very few states have opted to mandate services to these children (Cohen, Semmes, & Guralnick, 1979). Goldberg and Wolk (1976) note the absence of regulations from an agency such as the Department of Education for early intervention programs. In short, many authors appear to be calling for greater governmental participation in coordinating and promoting early intervention programs.

3.0 METHODOLOGY

3.1 Selection of Subjects

The population under consideration included all parents with children in early intervention programs in New Jersey. A sample was selected from this group based on the following criteria: (1) the child had to have been enrolled in a program for at least two months, to ensure that parents had a certain degree of knowledge about the program; (2) the child had to be under 3 years old (0-3 is the age group generally served by early intervention programs; programs that serve children between the ages of 3 and 5 are usually termed "pre-school" programs).

The early intervention programs included in the study were associated with the Coalition of New Jersey Infant Program Administrators, which represents all but three or four programs in the state. Most importantly, the Coalition includes all programs that have had direct contact with the Developmental Disabilities Council through the formula grants program.

3.2 Participation of Subjects

Participation of both parents and program staff was relatively high, as shown in Table 3.

Table 3. Sample and Level of Participation

	Total Population	Total Sample	Total Respondents
Parents	564	433	328[a]
Programs	29	29	26[a]

[a] Two programs supplied only limited data.

Of the total population, 131 parents were newcomers to programs and therefore were not included in the total sample figure. Of the total sample, 74% of the parents responded, and 83% of the programs were able to participate in all aspects of the data collection process.

3.3 Research Design

The questions to be addressed made it necessary to develop an ex-post-facto research design. A number of different methods were employed to collect information. The Council wanted to secure data on children and their functional capabilities, on each program, on perceptions of both staff and parents regarding results of programs, and finally on parent satisfaction. Five separate methods of data collection were devised, the first three of which were written instruments:

- Program Administrator Survey
- Parent Questionnaire
- Functional Assessment Form
- Group interviews with staff and parents
- Phone interviews with program administrators to collect information on monitoring and evaluation procedures used by programs

The three instruments and protocols for the interviews can be found in Appendixes A-E.

The data collection procedures used in the study are summarized in Table 4.

Table 4. Sequence of Data Collection Procedures

Steps	June	July	Aug.	Sept.	Oct.	Nov.	Dec.
Met with Coalition members to secure participation	—						
Developed instruments	—	—	—				
Mailed survey kits to program administrators			—				
Agencies mailed out Parent Questionnaires to all eligible parents				—	—		
Made follow-up phone calls to program administrators				—	—	—	
Received forms				—	—	—	—
Conducted site visits for group interviews				—	—	—	—

Many members of the DD Council's Executive Committee and of the Coalition of New Jersey Infant Program Administrators were concerned about protection of clients' confidentiality. In order to maintain such confidentiality, a set of code numbers was assigned to each eligible parent and child. However, to allow for analysis of data by program, each agency maintained a master code by recording assigned numbers.

To facilitate the mailing and response process, pre-stamped envelopes were distributed to all centers. Flow charts describing the data collection process were also provided.

Site visits to all programs were made between September and December, 1979. Typically, an hour and a half was spent with parents in the morning and the same amount of time with staff in the afternoon. Interviews were conducted in a group format. To help generate open discussion, staff were excluded from parent interviews. The same interview protocol was used with both parents and staff in order to foster different perspectives regarding the same set of issues. The interviews furnished information on the basic structure of the programs, how expectations of parents were handled during intake, accomplishments of the programs, positive and negative aspects of programs, and any other issues that participants considered important to share. On the average, 25% of the parents from each center participated. Although the data gathered from the interviews cannot be viewed as totally representative, it is presented in this report in lists and in summary statements to highlight various results.

The final aspect of the research design involved phone calls to each program administrator for the purpose of gathering additional data on monitoring and evaluation procedures. Calls were made during the months of February and March, 1980, by DDTRC staff. Telephone interviews helped to clarify various administrative practices and to supplement information gained from the Program Administrator Survey.

3.4 Instrument Development

Each instrument underwent a number of revisions during construction. Input from prominent professionals as well as parents was sought to assure that the instruments would provide the information needed to address the Council's concerns.* After the initial development of the Program Administrator Survey and the Parent Questionnaire, both forms were pretested. Based on the pretests, questions were reworded, additional questions were added, and written procedures for filling out the forms were revised. Subsequent drafts of the two instruments were also reviewed by the Council's executive director.

An instrument entitled the "Functional Assessment Form" (FAF) was developed to assess the functional capabilities of children in the programs.** This form consisted of a forty-item behavioral checklist divided into four developmental areas--gross motor, fine motor, language, and social/personal. The FAF was adapted from the Denver Developmental Screening Test (Frankenberg and Dodds, 1967) by selecting items that would meet three criteria:

- Appropriateness of behavioral items for children under 3
- Ability to assess item without formal testing procedures
- Relevance of item to early intervention programs

The final selection of ten items in each of the four developmental areas was made through consultations with experts in the field.***

The FAF was designed to provide a rating of the functional capabilities for each child. A developmental quotient can be represented as follows:

$$\text{Developmental Quotient} = \frac{\textbf{Current Developmental Ability of Child}}{\text{Expected Developmental Ability for the Child's Age}}$$

A 1½ year-old child with a developmental quotient of 1.00 would be exhibiting all behaviors expected for children of that particular age. Children with a developmental quotient of .54 would be functioning at 54% of the expected level for their age. Thus, any developmental quotient can be translated into a percentage of "normal" or expected development. Developmental quotients for each child were calculated in each of the four developmental areas; these quotients are used throughout the report whenever functional capabilities of children are described.

Scoring procedures used to establish the developmental quotients were based on those used in the United Cerebral Palsy's **Evaluation Report** (Meisels, 1976), a report that assessed the impact of a nationwide collaborative project of early intervention programs. The UCP report used the same age norms that were calculated in the initial Denver Developmental Screening Test. The details of the scoring procedures and age norms associated with each of the forty items on the Functional Assessment Form are presented in Appendixes F and G.

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* Berta Raphael, Director of Early Education, United Cerebral Palsy of New York City; Estelle Schwartz, Program Administrator, First Chance, New York City; and Ronnie Gordon, Director of the Pre-School Infant Development Program, Institute for Rehabilitation Medicine, reviewed the Program Administrator Survey. Fifteen Parents from UCP and First Chance early intervention programs reviewed the Parent Questionnaire.

** Dr. Lawrence Taft, a member of the Executive Committee of the New Jersey Council, assisted in development of the FAF.

*** Dr. Taft and Dr. Gordon Williamson, program administrator of the early intervention program at the John F. Kennedy Rehabilitation Center in Edison, New Jersey, assisted in this process.

The FAF was filled out by a staff member currently working with the child. In addition, the FAF was included in the Parent Questionnaire. In order to gather data on expectations as well as current functional levels, it was decided to include projected levels of functioning (at age 3) for each child. Therefore, comparisons between parent and staff views of the child for both present and expected future functioning were possible.

The greatest concern during the development of the FAF related to its validity. When significant modifications are made on a well-known instrument, such as the Denver Developmental Screening Test, the psychometric properties of the original instrument cannot be claimed for the revised instrument. While time constraints did not allow for a full psychometric review of the FAF (e.g., its reliability), procedures to determine the criterion validity of the FAF were performed during February and March, 1980. In order to assess the association between the FAF and the full Denver Developmental Screening Test, DDTRC staff trained in the administration of the Denver Developmental Screening Test visited two early intervention programs in New York City--the Guild for Exceptional Children in Brooklyn and the United Cerebral Palsy Center of Queens. While DDTRC staff administered the Denver, staff members at each center filled out a Functional Assessment Form for each child being tested. With a sample totaling twenty from both centers, the results shown in Table 5 were obtained:

Table 5. The Relationship Between the Denver Developmental Screening Test and the Functional Assessment Form

Gross Motor	Language	Fine Motor	Social/ Adaptive
.83	.58	.78	.59

Each of these Pearson Product Moment correlations were significant at the .01 level. The correlations are sufficiently strong to provide reasonable confidence that results from the FAF represent a valid picture of a child's functional capabilities.

3.5 Limitations of the Study

Before examining the project results, the reader should note the following limitations of the study:

- Data were collected primarily during the months of September and October, when many of the programs were reconvening after summer vacation. With a fairly large turnover in clients served in these programs, results such as population characteristics might be affected by the timing of the data collection. For example, a program which reports 15 children in September may be up to 25 or 30 children by mid-year.
- Much of the information was obtained through self-report. This method can foster problems such as biases in the responses or a "halo effect," where everything appears "rosy" and programs can do no wrong.
- Participants in the study may have feared that negative comments would jeopardize the future existence of funding of the programs. Despite assurances of anonymity and the emphasis of the study on looking at programs together, not individually, fears about the effects on particular programs existed. These dynamics may have contributed to the overall positive skew in the parent satisfaction measure and the relatively low number of suggestions about needed improvements in the programs.
- A number of bivariate analyses are presented in the results (e.g., how a program director's educational background is related to parent satisfaction). Caution needs to be exercised in interpreting these relationships, particularly when assuming that a cause and effect relationship exists between the two variables. At best, only a significant association between any two variables can be established by the study.

3.6 Summary of Methodology

After careful preparation of the instruments to be used in the study, centers affiliated with the Coalition of New Jersey Infant Program Administrators were mailed a package containing all necessary forms and instructions. Staff at each center mailed the Parent Questionnaires to eligible parents and subsequently returned a Program Administrator Survey. Functional Assessment Forms were also completed for all children of participating parents. During the fall, site visits were conducted at all programs that were in full operation. Parents and staff were interviewed. Finally, telephone interviews were conducted with each program administrator to gather information on monitoring and evaluation procedures.

4.0 FINDINGS

Results of the study, organized by topic area, are detailed in the following four sections:

4.1 - Characteristics of the Service Population
4.2 - Factors Related to Entering a Program
4.3 - Characteristics of Program
4.4 - Perceived Outcomes of Programs

In some of the tables statistical information is provided. The abbreviation $\overline{X}$ will be used to signify the mean; SD, to signify standard deviations; and X^2, to signify a chi-square. The number of responses (N) may vary slightly from table to table because of missing data or inappropriate answers.

4.1 Characteristics of the Service Population

Analysis of demographic data serves at least two important functions. First, summary descriptions of the population being served help to determine the degree to which all segments of the general population are being served. Second, the absence or presence of various characteristics within the service population may have important implications for program design and impact.

4.1.1 Parents

Overall, a wide spectrum of ages are represented by the population of parents, ranging from parents in their teens to others over 35. Mothers tend to be somewhat younger than fathers. As shown in Table 6, relatively few parents fall within the younger end of the continuum; 13% of the mothers and 7% of the fathers were 23 or under.

Table 6. Age of Parents

	Mothers[a] (N = 313)	Fathers[b] (N = 293)
Under 20	2%	1%
20-23	11%	6%
24-27	24%	14%
28-31	21%	25%
32-35	20%	20%
Over 35	22%	34%

[a] For mothers, $\overline{X}$ = 29.8, SD = 5.4.

[b] For fathers, $\overline{X}$ = 32, SD = 4.4.

A wide spread in the educational background of parents was also found, as shown in Table 7. While the majority of parents had received at least some college training, a substantial proportion were at the lower educational levels (i.e., high school graduate or below). The majority of mothers (54%) possessed a high school degree or less. In general, mothers tended to have attained lower educational levels than fathers.

Table 7. Highest Grade Level Attained by Parents

	Mothers (N = 313)	Fathers (N = 292)
Graduate/professional school	15%	16%
College degree	13%	19%
Some college	18%	22%
High school graduate	38%	27%
Some high school	10%	11%
Junior high completed	4%	4%
Under 7 years of school	2%	1%

The levels of family income among parents also displayed wide variation, as shown in Table 8. All income levels are reasonably represented, with 11% of the families receiving some form of financial assistance, such as Supplementary Security Income. The typical family's income is just over $15,000. The median income for a family of 4 in New Jersey is $21,409 as of July 1, 1979.

Table 8. Total Family Income[a]
(N = 295)

Receiving financial assistance	11%
Under $5,000 (Not receiving assistance)	2%
$5,000 to 10,999	17%
$11,000 to 16,999	21%
$17,000 to 22,999	24%
$23,000 to 28,999	12%
$29,000 to 34,999	6%
$35,000 and above	7%

The occupations of heads of households have been grouped into seven categories. The occupational classifications noted in Table 9 were established by Hollingshead (1957), and each subsumes approximately 30-50 more specific occupations. While some parents have jobs that are characteristic of higher classes, the majority of occupations held by heads of households fall in the lower part of the scale; 54% have jobs represented by the bottom four classes.

In order to summarize the family background of children, a picture of the families' socioeconomic status was developed by using the formula created by Hollingshead (1957). This formula takes into consideration both occupational class and educational level in determining social class. Families seem to be evenly distributed across the higher and lower ends of the socioeconomic scale. In examining the two extreme ends of the scale, one finds more families in the lower than in the upper class. The mid-lower and lower class categories together comprise more than one out of every three families.

Table 9. Occupational Class for Head of Household

(N = 291)

Class	Description of Occupation	Percentage
1	Higher executives of large concerns, proprietors, and major professionals	11
2	Business managers, proprietors of medium-sized businesses, and lesser professionals	21
3	Administrative personnel, owners of small businesses, and minor professionals	14
4	Clerical and sales workers, technicians, and owners of little businesses	14
5	Skilled manual employees	20
6	Machine operators and semi-skilled employees	9
7	Unskilled employees	11

Table 10. Socioeconomic Status of Families

(N = 288)

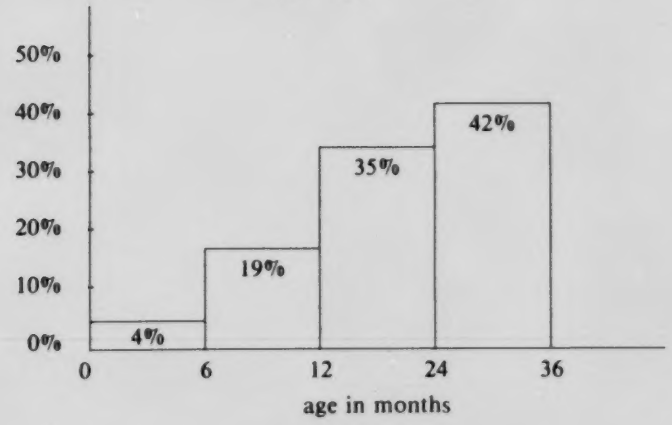
Upper class	11%
Mid-upper class	27%
Middle class	27%
Mid-lower class	18%
Lower class	17%

4.1.2 Children

While the previous set of tables focuses on parents, the following group of data describes various characteristics of children. Table 11 indicates the age breakdown of all children in programs during the fall of 1979.

Table 11. Age Breakdown of Children

(N = 564)



The age breakdown of children is skewed towards the older end of the age continuum. The mean age for all children was 20.6 months (SD = 8.8). Nearly half of the children (42%) were over 2 years old. Caution needs to be exercised in understanding the significance of these figures. The data were collected at the beginning of the school year and new children added to the program's roster in succeeding months may tend to be in the lower age brackets. If this is the case, the age breakdown would become more evenly distributed.

With respect to the ethnic background of children, most are Caucasian, with 29% from minority backgrounds. While data in this report are presented only in group format, individual centers were examined to determine whether there were large differences among the centers regarding minority participation. There were in fact some noticeable contrasts. Ten of the twenty six centers had only one or two children from a minority background. Whether the disproportionately low minority representation of these centers reflects the ethnic characteristics of the surrounding community could not be determined within the scope of this report. Nevertheless, an analysis of the data does point out that most of the minority children participate in a relatively small number of programs.

Table 12. Ethnic Background of Children

(N = 564)

Caucasian	71%
Negro	17%
Hispanic	10%
Asian	1%
Other	1%

Another important element of the home life of children in programs is where and with whom they reside. More than 75% of the children live with both parents and 94% live with at least one of their original parents (see Table 13). If we examine the home environment by center or program, a different picture emerges. At the typical center, 60% of the children are living with both parents and 31% with one parent. This apparent discrepancy from the overall figures reflects the fact that some centers have a very high percentage of children living with both parents, while for others the single-parent family is more typical.

Another aspect of home life relates to the presence of siblings. During the group interviews, a number of parents indicated that if siblings were included during treatment sessions, this represented an important feature of the program. Staff also pointed out that a secondary gain of the program was that parents became better caregivers with siblings due to parents' overall increase in parenting skills. Two-thirds of the children in programs have at least one brother or sister living with them.

Table 13. Home Environment of Children

(N = 564)

	Where Child Lives					Presence of Siblings	
	With Both Parents	With One Parent	With Relatives	In Other Residences	Other	None	One or More
Total	77%	17%	2%	3%	1%	33%	67%
Center Mean	60%	31%	3%	6%	1%	32%	68%
Center SD	17%	13%	3%	5%	1%	13%	13%

The final pieces of descriptive data on children relate to their particular developmental disabilities. Staff members provided diagnostic classifications for most of the children whose parents returned a Parent Questionnaire. Down's Syndrome was clearly the most frequently cited diagnosis, followed by developmental delay. Developmental delay is often used as a descriptive diagnosis to signify that while no clear disability, such as cerebral palsy, can be seen, the child is significantly behind children of his/her age in attaining developmental milestones. Whether the delays will be corrected or whether a more identifiable disability will emerge in the future cannot be determined with great certainty at the time of diagnosis.

Table 14. Diagnostic Classifications
(N = 298)

	N	%
Down's Syndrome	72	24
Developmental delay	65	22
Cerebral Palsy	53	18
Mental Retardation	40	13
Other orthopedic problems	20	7
Other neurologic problems	14	5
Language/hearing/visual problems	6	2
Spina Bifida	4	1
Genetic Syndromes	3	1
Other	21	7

Another way to describe the particular disabilities of children attending early intervention programs is to calculate the average functional capabilities. Staff ratings were used in Table 15 below. The children are typically most delayed in the gross motor area. The capabilities of children are relatively similar in the other three areas. However, within each area, there is a reasonably high degree of variation. The social/personal area demonstrates the greatest differences among children while gross motor skills are the most homogenous.

Table 15. Developmental Quotients of Children

	N	Mean	SD
Gross motor	237	.40	.24
Fine motor	235	.53	.28
Language	236	.51	.28
Social/personal	229	.50	.30

4.1.3 Summary

The key findings regarding the demographic characteristics of parents whose children are enrolled in early intervention programs are the following:

- A wide range of ages are represented by parents, with the largest grouping of mothers between the ages of 24 and 27 and the largest grouping of fathers over 35.
- Data on the educational background of the parents shows that the majority of mothers possess a high school degree or less and the majority of fathers have had at least some college education.

- All income levels are reasonably represented. The median income is just over $15,000.
- Fifty-four percent of the heads of household have jobs in either skilled, semiskilled, or unskilled labor trades; 46% are employed in administrative, management, or professional work.
- Families are evenly distributed across the higher and lower ends of the socioeconomic scale, with more families in the lower class than in the upper class.

With respect to infants enrolled in these programs, the key findings are as follows:

- The mean age for children is 20.6 months. Forty-two percent of the children are over 2 years old.
- The majority of the children are Caucasian; 29% are from minority backgrounds.
- More than 75% of the children live with both parents and 94% live with at least one of their original parents. Two-thirds of the children have at least one brother or sister living with them.
- Thirty-six percent of the children are diagnosed as having developmental delay, 26% as having Down's Syndrome. The remaining 38% have disabilities, the most common being cerebral palsy and orthopedic problems.
- Typically, children were found to be most delayed in gross motor skills; they exhibited the greatest differences in ability in the social/personal domain.

4.2 Factors Related to Enrollment in a Program

Choosing to enroll one's child in an early intervention program involves a complex set of events. Components of the entry and intake process examined in this study included the need for services, ways that programs publicize their services, ways in which parents first learned of programs, the actual enrollment process, transportation concerns, and the physical settings of programs.

Many comments made during the group interviews underscore the fact that there was diversity in what parents confronted during the intake process. For some, all parties involved were quite understanding and genuinely helpful. For others it was difficult to find the appropriate resources and come to the decision to enroll their child in a program. These differences need to be kept in mind when assessing the trends found in the data related to enrollment in a program.

The complexity of parents' decision to enroll their child in a program also needs to be emphasized when considering the extent to which New Jersey is meeting the need for early intervention programs. The use of statistical estimates for children presumably needing early intervention services does not take into account the many parents who are unwilling or unable to have their child participate in a program. Transportation problems, a doctor's lack of confirmation of a developmental difficulty, parental differences in whether a problem exists, and a parent's ability to recognize a developmental problem are examples of limitations to enrolling a child in a program. Therefore, one should not examine the statistical estimate of children in need and expect that every child should be in a program. In short, while there is an unmet need for services in New Jersey, statistical estimates may tend to overinflate the size of this gap.

4.2.1 Determining the Need for Services in New Jersey

Prevalence rates for persons with developmental disabilities differ depending on the conceptual rationale used to calculate the figures. Boggs and Henney (1979) established that a 3% prevalence rate would be reasonable for predicting how many children under age 3 need early intervention services. This figure is somewhat higher than the general prevalence rate used to characterize the developmentally disabled population of all ages (1.5-2%, EMC, 1979). Boggs and Henney reasoned that early intervention programs, because they are serving a preventive function, should include the broader diagnosis of developmental delay. The 3% figure represents those children who are, and also those who may potentially become, developmentally delayed.

Boggs and Henney attempted to adduce from the data reported in the 1976 Survey of Income and Education (SIE) some age specific rates of prevalence for developmental disabilities. They concluded that less than 2% of the school age population (3-17) would qualify and less than 1½% of adults. SIE did not cover children under 3. Boggs and Henney suggested that as many as 3% of this age group could be found eligible for services under the DD Act (P.L. 95-602) based on the Act's mandate for priority to prevention services within the context of early intervention. Thus the 3% includes not only those children who manifest functional limitations but those "at risk". It is assumed that this could include, for example, low birth weight infants, or abused infants, as well as those with non-specific developmental delays and specific conditions (such as Down's Syndrome or spina bifida) with a high probability for future confirmation of functional limitations and long term care needs as delineated in the statutory definition of "developmental disabilities".

Although this liberal approach would permit the use of funds under the Act for programs for infants "at risk" who do not yet manifest developmental delays or specific conditions, the New Jersey programs in this study do not fall in this category. Although our survey did not explicitly cover the criteria for admission to the programs, it is clear that most of the infants either have a specific diagnosis or actually exhibit significant functional limitations relative to norms for age(Table 14, 15).

The universe from which the enrollees are drawn is thus limited by two factors - the presence of recognizable developmental delays, such as gross motor retardation, and the acceptance by the parents of the need for intervention. The SIE provides some insights into the degree to which pre-school children are recognized as having "activity limitations" attributable to some "health condition". Of approximately 6 million children who were between age 3 and 5, 178 thousand non-institutionalized children were found by SIE to be reportable by their families as having a limiting health condition. Of these only 30% were specifically identified as falling into the categories most likely to meet the "DD" test - having a functional limitation in areas of sensory, motor, language, cognitive or social functioning. Thus among 3 and 4 year olds, 2% are reported as recognized by their families as having an activity limitation (primarily defined as difficulty in participating in age appropriate play); only 0.6% were known to be either mentally retarded, visually or hearing impaired, orthopedically handicapped, or seriously emotionally disturbed or delayed in language development. Since recognition by both parents and professionals increases with age, these percentages present us with an upper limit on what might be expected in the age group 2-3, especially when one considers that speech delay becomes more pronounced after age 3.

According to the parents of the children enrolled in New Jersey programs studied in fall 1979, 99% knew that their child had a problem by age 2, and 92% of the children had been enrolled prior to that age. Two year olds enrolled constitute approximately ¼% of all two year olds in the state.

Table 16. New Jersey Population Figures[a]

Total New Jersey Population	7,349,000
Under 5 Years Old	502,177
Under 3 Years Old	301,306[b]
Estimate of Need	6,026[c]
Total Children Being Served	564

[a] Population figures are 1978 estimates published by the New Jersey Department of Health, **Provisional New Jersey County Population Estimates by Age, Sex, and Race**.

[b] The report cited above presents estimates only for children under 5. The statistical estimate of children under 3 was calculated by taking 60% of the under 5 figure.

[c] A prevalence rate of 2% was used to determine the estimate of children in need of early intervention services of the type provided in these programs.

Thus using the SIE 3-4 year old rate for all limiting health conditions, it can be estimated that in the fall of 1979, programs were providing services to approximately 12% of those 2 year olds recognized to be in need.*

Another issue involved in determining the need for services is whether the geographical location of programs matches the presumed need in that area. By ranking counties according to the number of children under 3, it was determined that a signifi[illegible] relationship exists between enrollment and population within each county (Spearman Rho cor[illegible]n coefficient = .55, p is less than .01).

Table 17. Attendance in Programs by County Compared with Estimated Need

(N = 564)

	Total Population Under 3	Rank In Population	Attendance In Programs	Rank In Attendance	Ratio of Attendance/ Population (Need)	Rank In Need
Atlantic	7,790	15	35	8	.00449	18
Bergen	35,473	1	24	11	.00067	4
Burlington	14,903	10	18	14	.00121	9
Camden	19,335	7	42	4.5	.00217	12
Cape May	3,157	20	12	16	.00380	17
Cumberland	5,338	16	25	10	.00468	19
Essex	34,025	2	42	4.5	.00123	10
Gloucester	8,200	14	28	9	.00341	16
Hudson	22,714	4	11	17	.00048	3
Hunterdon	3,452	18	19	13	.00550	20
Mercer	13,005	12	72	1	.00553	21
Middlesex	24,235	3	69	2	.00284	15
Monmouth	20,495	6	45	3	.00219	13
Morris	16,564	9	13	15	.00078	6
Ocean	13,591	11	37	7	.00272	14
Passaic	19,138	8	23	12	.00120	8
Salem	2,558	21	1	20	.00022	2
Somerset	8,519	13	6	18	.00070	5
Sussex	4,447	17	0	21	.00000	1
Union	20,893	5	38	6	.00181	11
Warren	3,444	19	3	19	.00087	7
Other State			3			
Totals	301,306	564				
State Average					.00186	

* The 12% figure was arrived at by taking 2000, the estimated number of 2 to 3 year old children needing service, and dividing by 237, the number of 2 to 3 year old children currently receiving service.

As seen in Table 17, there were, however, noticeable differences in some of the rankings. Despite being ranked fourth in population, Hudson County ranked seventeenth (out of twenty-one counties) in the actual number of children being served. On the other hand, some counties had a higher rank in attendance than would be expected from their population under 3. For example, Mercer County is ranked twelfth in population, yet had the most children in attendance in all the programs.

An estimate of need was determined by calculating a ratio which divided the number of enrolled children in each county by the number of children under three for the particular county. Counties that could be characterized as less densely populated and rural appeared to be most in need (Sussex and Salem). However, two densely populated and urban counties (Bergen and Hudson) were also rated high in estimated need.

Table 18. Publicizing Services Offered by Programs
(N = 26)

Type of Publicity	Never[a]	Rarely[a]	Sometimes[a]	Often[a]	Constantly[a]
Distribution of brochures/ program descriptions to parents and others visiting the program	12%			34%	54%
Contacts with referral sources such as community or county agencies			19%	35%	46%
Contacts with local hospitals		12%	15%	46%	29%
Contacts with doctors in private practice		8%	34%	23%	34%
Contacts with prenatal or genetic counseling centers	15%	23%	19%	19%	23%
Talks to community groups (e.g., PTA, Elks, etc.)	12%	23%	27%	19%	19%
Distribution of brochure, program description in locations outside the center (e.g., libraries)	19%	15%	27%	34%	4%
Mass media (e.g., TV, radio)	4%	34%	46%	12%	4%

[a] On the Program Administrator Survey, precise definitions were provided for these terms as follows:

never (have never attempted this at all)
rarely (have tried this once or twice this year)
sometimes (have tried this about 3-4 times this year)
often (do this almost every month)
constantly (do this a number of times a month)

Another way of conceptualizing whether programs are meeting the existing need for services is to examine their geographical location across the state. Overall, programs are distributed throughout the state. However, there does seem to be some distinguishable patterns. There are a few clusters of programs most notably around the Camden, Edison, and Union areas. In addition, the rural areas along the southern and northern borders of New Jersey appear to have fewer programs available to them than other geographic regions.

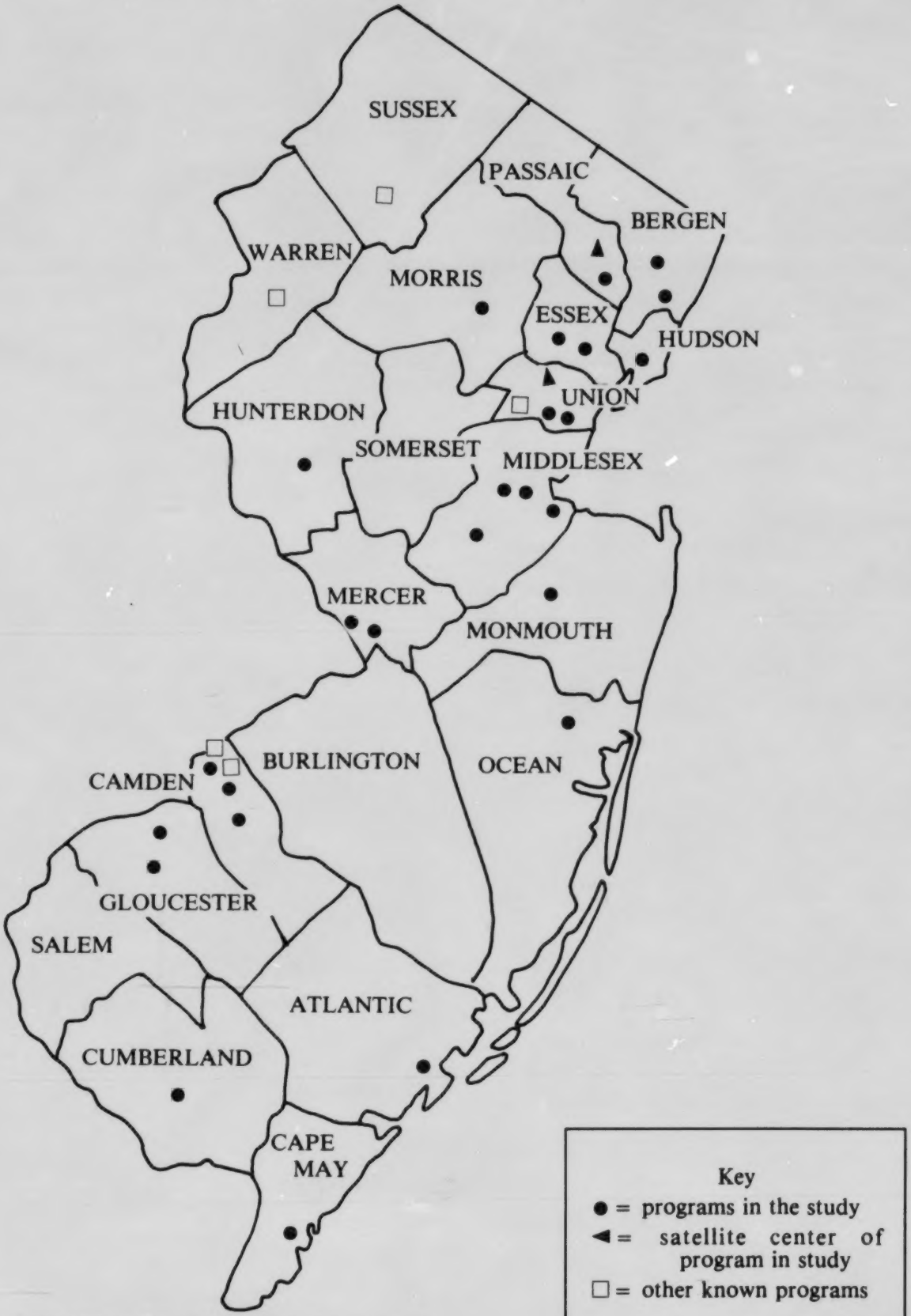


Figure 1. Location of Early Intervention Programs

4.2.2 Publicizing Service Availability

With less than 15% of the estimated population in need being served, publicizing the existence of services is an important program function. Programs use a variety of methods to raise community awareness (see Table 18). As a whole, the highest level of activity involves contacting community or county agencies as referral sources. Mass media publicity appears to be the technique used least frequently.

The strategies for informing the community about the availability of early intervention programs can be separated into activities directed toward professionals and those directed toward consumers or potential consumers. Based on the responses of program administrators, it appears that the former strategy is more prevalent.

4.2.3 Learning about Programs

Another facet of the enrollment process is how parents themselves first heard about the early intervention program. The most frequently cited information source was doctors (40%), who together with other professionals accounted for 77.5% of all referrals. For 17% of cases, parents first learned about the program from a more informal network of contacts such as friends, relatives, and other parents.

Table 19. How Parents First Heard about the Program
(N = 322)

Information Source (in rank order)	%
Doctor	40
Friend or relative	12
Hospital social services person	11
Hospital staff	8
Other	6
Another parent with child in program	5
Home visiting nurse	4
Prior knowledge	3
Their own search	3
Health clinic or similar agency	3
Voluntary developmental disabilities organizations like UCP or ARC	2
Media	2
Division of Youth and Family Services	2

4.2.4 Enrolling in a Program

Finding out about early intervention programs is only one aspect of actually enrolling a child in the program. The entire sequence can be described as a four-step process, although the order may vary for some parents. Typically, parents suspect the existence of a problem and seek help from a professional. In a variety of ways, they then learn about programs and eventually enroll their child. Underlying this sequence is the critical issue of length of time between parents' knowledge of their child's special limitation and enrollment in a program.

Within the first three months, nearly two-thirds of the parents at least suspected that their child had some special difficulty. Almost half noticed right at birth that their child might have particular limitations; about the same proportion were given that information by doctors immediately after the birth. Overall then, there is a reasonably close relationship between when parents first notice the developmental problem and when a professional informs them that their child has special needs.

Table 20. Timing of Events Related to Entering a Program

		Age in Months						
	N	Birth	1-3	4-6	7-9	10-12	13-24	24+
When parent first noticed child might have special difficulties [a]	310	42%	25%	13%	8%	6%	5%	1%
When parent was first told by a professional that child had special difficulties [b]	310	44%	17%	11%	8%	7%	12%	1%
When parent first learned about the program [c]	303	13%	22%	17%	8%	14%	19%	7%
When child started the program [d]	307	1%	20%	19%	13%	13%	26%	8%

[a] $\overline{X}$ = 3.7 months, SD = 4.8

[b] $\overline{X}$ = 4.6 months, SD = 6.4

[c] $\overline{X}$ = 8 months, SD = 1.4

[d] $\overline{X}$ = 9.4 months, SD = 6.6

However, despite this knowledge about their child, a certain number of months typically pass before the parents learn about the existence of a program. Of those parents who knew their child had special difficulties by the time he/she was 3 months old or less (61%), a much smaller number knew about programs. An average time of nearly three and a half months went by before parents learned about a program.

During the group interviews, parents provided a number of comments that help to explain how a number of months can pass before a parent learns about a program. The factors related to this delay include the following:

- Lack of a central place or listing to find out about early intervention programs
- Claims by doctors that nothing can be done about the course of the child's development, or that the child should be institutionalized
- Claims by doctors that nothing is wrong with the child
- Lack of knowledge among doctors and other professionals about the program
- Feelings of isolation

Another issue related to enrollment is the gap between when parents do learn about a program and when their child actually starts the program. Only 28% of the parents reported that they enrolled their child immediately upon hearing about the program, although a large majority had their child enrolled in a program within four months (84%). The average time gap was approximately two and a half months.

As noted previously, a number of factors influence when a child starts participating in a program. One of these factors may be that some parents encounter a waiting list when they call a program and want to enroll their child. Eleven programs report the existence of a waiting list at their center (42%). Those eleven centers have an average waiting time of nearly three months ($\overline{X}$ = 11.5 weeks). However, the meaning of "waiting list" needs to be carefully understood. The use of the term in this context does not necessarily imply that programs are filled to capacity. Of the eleven programs that claimed to have waiting lists, only two indicated that their program was at full capacity. Program administrators explain that it may take a number of weeks to process applications and to fully evaluate a child's appropriateness for the program. Parents are automatically placed on a waiting list until a final determination of the case can be made.

Table 21. Time Lapse between Parents' Learning about the program and Child's Enrollment in the Program

(N = 287)

Time in Months	Percentage[a]
none	28
1-2	39
3-4	17
5-12	14
more than 12	2

[a] $\overline{X}$ = 2.6 months, SD = 3.3

In the fall of 1979, 15% of the programs were at full capacity; 12% claimed to be below 50% of capacity; and one program was at 8% of capacity. The typical program (mean) was at 73% of capacity. If all programs operated at 100% capacity, 773 children could be served.

Table 22. Capacity Levels of Programs

(N = 26)

below 50%	12%
50-59%	7%
60-69%	15%
70-79%	31%
80-89%	12%
90-99%	7%
100%	15%

$\overline{X}$ = 73% capacity, SD = 21%

4.2.5 Transportation

Another factor in the entry process pertains to how children are transported to programs. During the group interviews, both parents and staff mentioned transportation as a problem. In fact, staff pointed out that certain parents were not able to enroll their child because of lack of transportation. In those programs where transportation was provided, parents were quite appreciative of the service. Interestingly enough, some staff members mentioned that there was a benefit to not having the program provide transportation. They feared that participation might be reduced in some cases if transportation was offered.

Information obtained in the Program Administrator Survey regarding transportation could not be quantified due to some centers' misunderstanding of the transportation question. However, analysis of the open-ended responses indicates that a large majority of the programs do experience transportation difficulties. Ten programs provide at least some transportation services while 15 do not. One center is a home-based program. For those programs that did not have their own transportation, this was a serious limitation in the program. Problems were related to the inaccessibility of programs to public transportation, the unavailability of cars for some parents, the unreliability of friends or relatives for transporting parents or child, and the cost of transportation. Some programs noted that the high cost of transportation was beginning to limit the frequency of home visits. In those programs providing or coordinating some form of transportation, difficulties included mechanical breakdowns in the vans or buses, children not being ready when the vehicle arrived, and unreliable community or county transportation services.

4.2.6 Intake

When parents do contact programs to enroll their child or are referred, programs handle the intake process in a variety of ways. A review of intake procedures for all programs suggests that six steps are usually involved (see Table 23). First, a staff member contacts the parents by telephone. In some cases, an over-the-phone intake form is filled out. Next, a home visit is made to informally assess the child, the family situation, and the home setting. Following the home visit, a team evaluation is held, at which the parents and child are present along with all staff members. Children are assessed in some programs through informal methods and in others through formal procedures such as administration of the Denver Developmental Screening Test or the Bayley Scales of Infant Development. Subsequently, staff meet to discuss the child and determine whether the placement is appropriate. Finally, a parent conference is held to discuss the evaluation and placement recommendation.

Programs did not report that intake procedures included a parent visit to observe the program or an opportunity to talk with other parents. In essence, it appears that parents do not examine programs to see if **they** want to enroll their child. Typically, parents are so relieved to find some help that their assessment of the program does not appear to be relevant at the time of enrollment.

Some programs shorten the entry process; for example, a child may be admitted to the program before a full evaluation is conducted. Other variations in the basic intake process include having an experienced parent bring a new parent into a program for the first time; assigning one staff member to be the case manager; and conducting an interview with the program's social worker to gather an extensive family history.

The issue of how much information is sought before a child enters a program varies widely. Some programs schedule medical and neurological examinations, while others request existing records from the family's doctor.

Additional information on the intake process was gathered during group interviews with staff and parents. When parents were asked for their reasons for enrolling their child in a program, they seemed to be puzzled by the question; the answer appeared obvious: to help their child improve his/her development. Because of their apparent bewilderment at the question, parents were not asked this after the first few interviews. Parents were also asked what they had been told by staff regarding what the program would accomplish for their child. A consistent response was given by parents to this question: Program staff promised no clear results. Often parents were told such things as, "We'll do the best we can", or "We'll take one step at a time and see how your child progresses." Most parents did not ask program staff at the time of intake what their child would be like at the end of the program; the majority of parents were concerned with managing the current circumstances and were thankful that at least some place offered the potential for help. Parents appeared comfortable with the lack of "promises" from program staff. In fact, parents indicated that starting with concrete, short-range objectives was particularly helpful at the time. Overall, parents came away form the intake process feeling more optimistic about the prospects for their child than when they had first called the program.

4.2.7 Physical Settings of Programs

A final factor that can affect the entry process is the location of the programs. How far parents live from a program affects its accessibility and may raise concerns regarding transportation. As shown in Table 24, the majority of parents (56 percent) live at least ten miles from the program. The average distance a parent needs to travel is a little over eight miles. Approximately one out of every five parents lives relatively close to the program site (1-4 miles away).

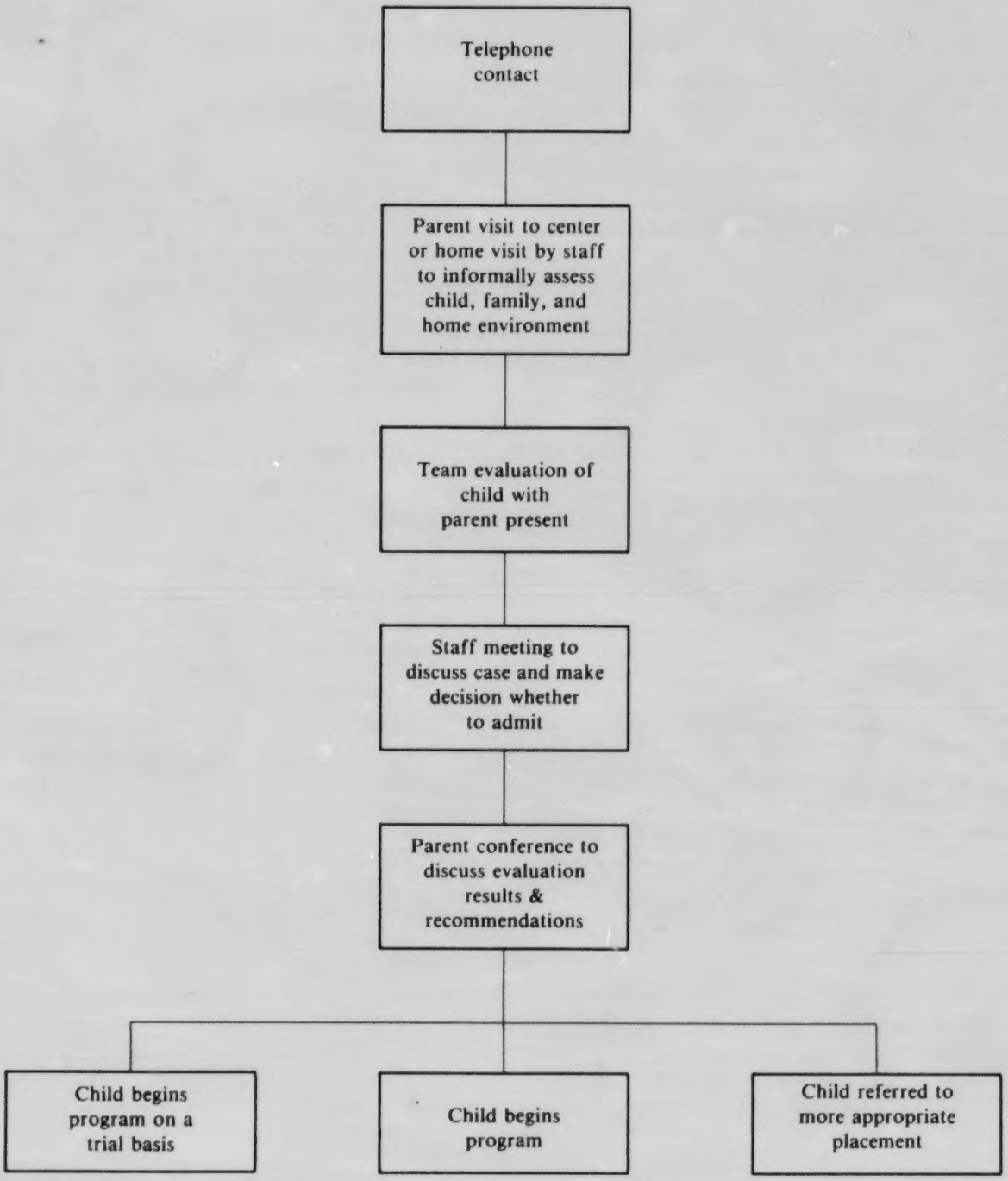

Telephone contact
Parent visit to center or home visit by staff to informally assess child, family, and home environment
Team evaluation of child with parent present
Staff meeting to discuss case and make decision whether to admit
Parent conference to discuss evaluation results & recommendations
Child begins program on a trial basis
Child begins program
Child referred to more appropriate placement

Table 23. The Basic Sequence of Intake Procedures

Table 24. How Far Parents Live From Programs
(N = 271)

Miles	%
1-4	21
5-9	23
10-14	25
15-19	11
20 and more	20

$\overline{X}$ = 8.3, SD = 6.2

In terms of where programs are actually housed, no clear pattern emerges. A variety of sites are used. Church settings are somewhat more frequently used, followed closely by hospitals and rehabilitation centers. Only one program is a totally home-based program. Occasionally, parents and staff mentioned that the site of the program had special meaning to them. For example, some parents like the fact that their center is not located in a hospital because hospitals imply the existence of some illness. As one parent reported, "My child is a well baby, not a sick one." However, some parents in hospital-based programs pointed out that the quality of care associated with hospitals was an attractive feature of the program. Other parents and staff objected to signs at centers such as "Association for Retarded Citizens." They said that they knew some parents who had refused to take their child to a center with such a sign because the child, in their opinion, was not retarded.

Table 25. Physical Settings of Programs
(N = 26)

Setting	Number of Programs
Church	7
Rehabilitation center	6
Hospital	6
Community agency/center	4
Special school	2
Home of parent	1

4.2.8 Summary

The total enrollment in early intervention programs is important when estimating the need for services in a particular area. Factors in enrollment include the methods by which parents learn of the existence of services, transportation issues, and the physical location of programs.

The following findings were noted:

- Enrollment in an early intervention program does not always follow immediately upon parents' being told of or noticing delays in their infant. On the average, parents do not learn of the existence of intervention services for approximately 3½ months; then, it is typically 2½ months until parents enroll their child in a program.
- If the program does not provide transportation, parents may encounter various difficulties or, in some instances, may be unable to enroll their infant. Transportation difficulties include inaccessibility to public transportation, high cost of transportation, and general unavailability or unreliability of private transportation. If the program does provide transportation, there are such problems as mechanical difficulties and delays (children may not be ready when the vehicle arrives).

- The basic steps of the intake process include the following:
  - phone contact
  - home visit by program personnel
  - team evaluation of the child
  - staff meeting to decide upon child's admission to program
  - parent conference to discuss evaluation results and recommendations
- With respect to physical location of the program centers, the majority of programs are over 10 miles away from the enrollees' homes and are located at a variety of sites, including churches, hospitals, and in one case, a parent's home.

4.3 Characteristics of Programs

Programs were examined for several broad factors that are likely to affect program operations and parental satisfaction. The factors examined were funding sources, monitoring and evaluation procedures, program models, and forms of parent participation.

4.3.1 Major Funding Sources

Programs appear to rely on a wide variety of funding sources for support of their services. A total of eleven different sources were indicated by program administrators as providing some portion of their budgets. Only two programs indicated that a single funding source supplied 100% of their operating income.

As shown in Table 26, nearly two-thirds of the programs collected at least some fee-for-service from parents. However, these fees typically accounted for a relatively low percentage of the program's income ($\overline{X}$ = 16%), ranging from 2% to 50%.

The second most frequently cited source of support was funds obtained from the Developmental Disabilities Council (administered by the New Jersey Division of Mental Retardation--DMR). More than half of the centers had received a grant from the Council. In these instances the grant usually accounted for a relatively sizable portion of the center's income (40%). However, this impact ranged considerably; for two-thirds of the centers, the grant was 16-64% of their overall income. (See page 4.33 for more details).

A number of centers reported receiving grants from a second state funding source--Special Child Health Services (SCHS) of the Department of Health. Almost the same number of grants were awarded by SCHS as by the Council. However, in terms of impact, centers reported that SCHS grants accounted for a smaller average percentage of their income ($\overline{X}$ = 19%). This percentage was relatively consistent for the fourteen centers receiving money from this source. In one instance SCHS monies accounted for 40% of a center's income.

Over a third of the centers received support from Title XX funds. There was a high degree of variation with respect to how influential this support was for a particular center. (The support ranged from a low of 3% of total funds to a high of 96%.)

A sizable portion of the centers were able to receive support from local or regional charities/clubs (44%). Relative to other funding sources, however, the average impact from this source was small ($\overline{X}$ = 19%). One center was able, however, to secure 58% of its budget from this source.

Although less than a third of the centers received funds from Medicaid and/or private insurance, for those that did the impact was relatively strong. On the average, this source of support represented 40% of a center's income ranging from a high of 67% to a low of 10%. If centers reported that they received money from insurance companies, the support was typically limited and restricted to physical therapy only. Centers which were successful in collecting third-party payments from private insurance companies were usually affiliated with a hospital.

Table 26. Funding Patterns of Programs
(N = 25)

Funding Source	Receiving Support	Range in % of Income (if receiving funds) Low	High	Overall % of Income (if receiving funds) Mean	SD
National philanthropic organizations	3	14%	50%	30%	18%
Special Child Health Services	14	1%	40%	19%	11%
Division of Mental Retardation/ DD/Council	15	13%	100%	40%	24%
Division of Special Education	1		100%		
Supplemental Security Income	1		2%		
Title XX	9	3%	96%	39%	36%
Charities/clubs	11	5%	58%	19%	15%
Fees from parents	16	2%	50%	16%	14%
Town/county government	7	3%	25%	13%	8%
Medicaid/private insurance	8	10%	67%	40%	22%
Other (e.g., hospital)	7	4%	50%	26%	15%

Table 27. Funding from Developmental Disabilities Service Grants

Fiscal Year	Total Federal Funds Available	Total for Infant Programs	Percent Allocated to Infant Programs
1971	$137,602	0	0
1972	519,939	$ 49,844	10%
1973	693,635	109,535	16%
1974	745,191	174,529	23%
1975	721,731	213,455	30%
1976	787,125	154,377	20%
1977	689,479	207,463	30%
1978	694,210	180,664	26%
1979	802,452	354,268	44%

Note: Data Source - New Jersey Division of Mental Retardation, Grants Management Office. In some years, totals for DDSGs may include funds carried over from the previous year because some programs did not actually spend the full amount allocated to them.

A more in-depth analysis was conducted on the funding patterns associated with the Developmental Disabilities Service Grants program, administered by the New Jersey Division of Mental Retardation. Since the DDSG program began in 1971, there has been a general trend towards allocating a greater proportion of the DDSG funds to early intervention programs. As Table 27 indicates, the percentage has increased from 10% of DDSG funds distributed to early intervention programs in 1972 to 44% in 1979. In addition, the actual number of programs receiving grants has steadily increased (14 in 1979). Any program that still operates an early intervention program has continued to receive a grant since the date of its first award; no program has had its grant discontinued. The range of continuous funding is from one to seven years. However, this does not imply that programs have been awarded a grant for the same program component year after year. Program expansion or different aspects of programs have often been the focus of grant renewals. The tables and figures on the following pages illustrate the trends mentioned above.

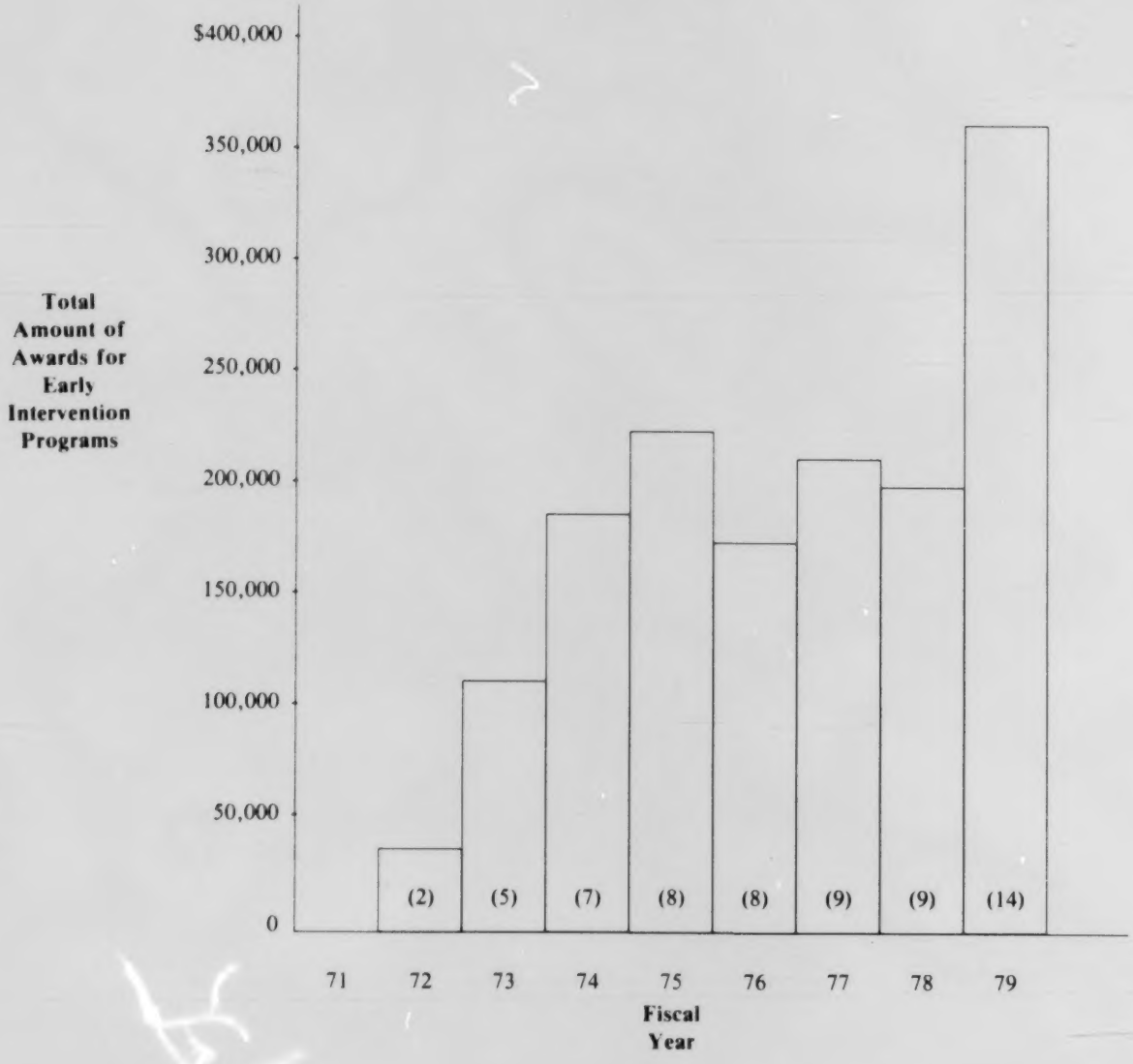


Fig. 2. Total Amount of Developmental Disabilities Service Grants Allocated to Early Intervention Programs

Note: Figures in parentheses refer to the number of awards made to an early intervention program.

Table 28. Pattern of Awards for Early Intervention Program Recipients: Developmental Disabilities Service Grants

SPONSOR	1971	1972	1973	1974	1975	1976	1977	1978	1979	Total
Center A	---	---	22,065	24,272	29,710	---	---	---	---	76,047
Center B	---	---	---	18,950	11,056	---	---	---	---	30,006
Center C	---	---	---	---	---	8,580	11,580	9,315	10,250	39,725
Center D	---	---	---	---	---	31,794	33,985	33,225	35,160	134,164
Center E	---	---	---	---	---	---	---	---	28,411	28,411
Center F	---	---	---	---	---	---	---	---	24,504	24,504
Center G	---	---	---	---	---	4,340	14,300	13,770	21,633	54,043
Center H	---	---	---	---	29,319	32,080	34,250	32,370	33,529	161,548
Center I	---	---	---	34,720	25,516	27,300	22,506	29,043	39,066	178,151
Center J	---	---	---	---	---	---	---	---	25,873	25,873
Center K	---	---	---	---	---	---	10,275	13,236	16,216	39,727
Center L	---	---	4,000	8,000	28,716	15,093	20,477	22,875	29,121	128,282
Center M	---	---	---	---	16,030	12,870	26,822	19,871	19,522	95,115
Center N	---	37,504	40,300	42,000	36,836	---	---	---	---	156,640
Center O	---	---	---	---	---	---	---	---	9,804	9,804
Center P	---	12,340	17,800	19,580	---	---	---	---	32,779	82,499
Center Q	---	---	25,370	27,007	36,272	22,320	33,268	6,959	28,400	180,496

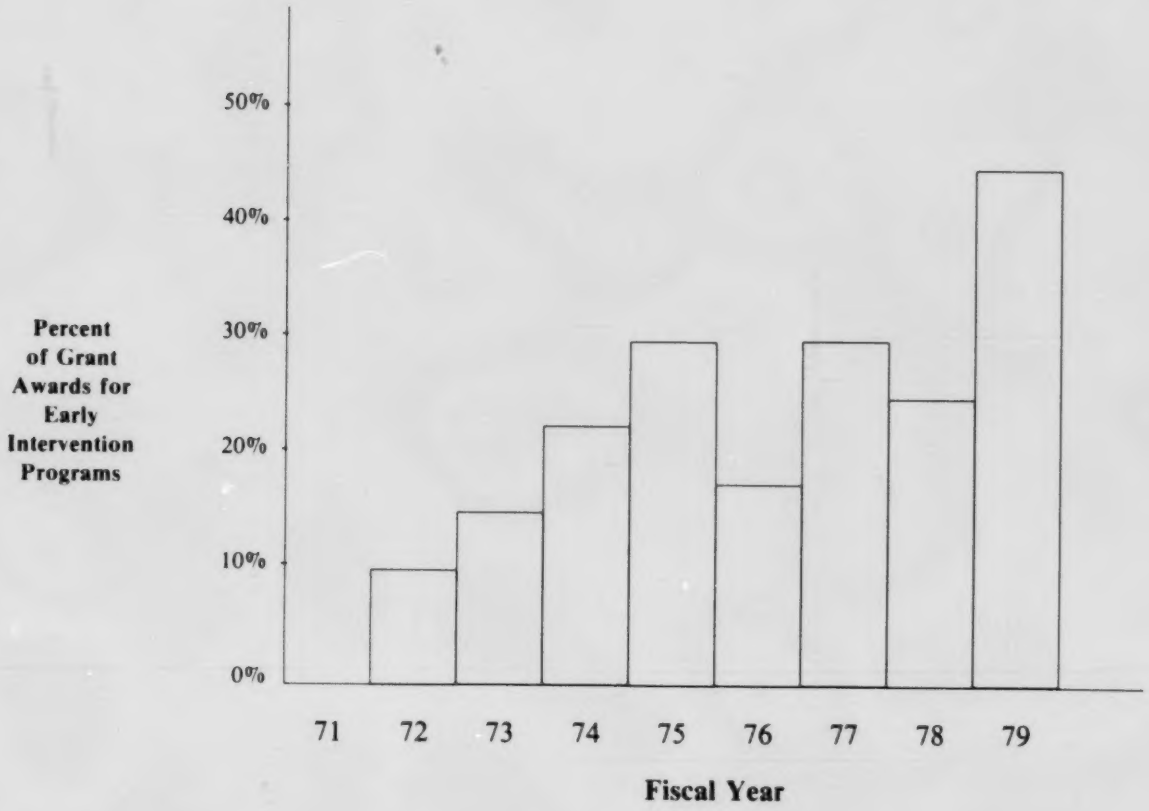


Fig. 3. Proportion of Total Developmental Disabilities Service Grants Allocated to Early Intervention Programs

4.3.2 Program Accountability, Monitoring, and Evaluation Procedures

The ways in which programs are monitored and evaluated were determined by asking program administrators to report on whether a number of typical practices existed at their center. As shown in Table 29, all centers indicated that they were accountable to a board of directors. However, most centers' boards are responsible for overseeing the larger organization with which the infant program is affiliated (e.g., a hospital or regional ARC operation). Therefore, it is unclear whether these boards have a significant monitoring role in the day-to-day operation of centers.

An important element in monitoring and evaluation procedures is the existence of an individual habilitation plan (IHP) for each child. Of those contacted, only one center did not have such a document in the file for each child. Despite this consistent finding among centers, much variation was found in what each IHP contained. All the plans had goals and objectives detailed for each child; nearly all noted the age of children; and most displayed the developmental level of the child. With respect to the particular goals and objectives for each child, approximately two-thirds of the programs distributed a summary of these objectives to parents on a regular basis. Centers varied considerably on other elements that could be in an IHP, such as sex, ethnic background, primary functional limitation, and documentation of parent involvement in the IHP's development. A number of centers reported that if the item was not included on the IHP, the information could be found in the overall record or file for the child.

Approximately three-quarters of programs have developed a written statement of the program's philosophy and purpose which could be distributed to new parents and visitors. Nearly 60% [illegible] the programs also had a statement available regarding the infant program's more specific goals and objectives.

A high proportion of programs reported procedures pertaining to staff evaluation. Every program except one had a policies and procedures manual for staff. With one exception, programs formally evaluated staff at least once a year. Over three-quarters of the programs included a written staff evaluation instrument.

Table 29. Accountability, Monitoring, and Evaluation
(N = 22)

	Presence of Procedure	
	Yes	No
Written statement regarding program's philosophy and purpose	73%	27%
Written statement of goals and objectives	59%	41%
Written evaluation plan for the overall program	27%	73%
Licensed by a local, federal, or state agency	32%[a]	68%
Governing board	100%[b]	
A policies and procedures manual for staff	95%	5%
Data analysis on changes in parents/children as a group	9%	91%
Written attendance records for children	86%	14%
Written attendance records for parents	50%	50%
Goals/objectives summary given to parents	68%	34%
Staff evaluation instruments	77%	23%

[a] Licensed by the New Jersey Division of Youth and Family Services.

[b] In a number of cases, boards were for an entire facility, not just the infant programs.

Most programs attempted to gather feedback from parents about the program. However, the means of accomplishing this varied. Fifty-nine percent of the programs collected these data by some formal procedure, while 36% relied on informal discussions with parents.

Monitoring by outside agencies or people represents another important means of accountability. Slightly less than one-third of the programs were licensed by a local, state or federal agency (32%), while only one-fourth received no evaluative feedback from external sources. Of those monitored by agencies such as SCHS or DMR, it was unclear whether programs considered these procedures to be formal or informal. Some programs received a written report from the licensing agency, while others were given no such report. Also, some centers were monitored on a regular basis, while others reported irregular contacts.

4.3.3 Program Models

As noted in the literature review, program models, as such, have not been delineated in the field of early intervention programs. In the absence of a clear framework, the issue of program model has been addressed by examining patterns that can have a major influence on services delivered. By this conception program models can in part be defined by the following:

- type of organizational affiliation
- staffing patterns
- parent participation in the classroom
- educational background of program administrators

Examination of program models could also include proportion of time spent in congregate activities in center based vs. home based programs. In view of the limited sample of home based programs (one program) in New Jersey this pattern was not examined.

Table 30. Accountability, Monitoring, and Evaluation - IHPs

	Presence and Nature of Procedure [c]			
	Yes: Informal	Yes: Formal	Yes: Both informal/formal	No
Staff evaluation procedures	5%	50%	45%	0%
Review of the overall service by program staff	45%	9%	41%	5%
Feedback from parents	36%	27%	32%	5%
Evaluation by people external to program	36%	32%	5%	27%
An individual habilitation plan (IHP)		95%		5%
If yes, the individual habilitation plan includes:				
age		95%		5%
sex		62%		38%
ethnic background		14%		86%
income range		5%		95%
address		67%		33%
developmental level or behavioral assessment		81%		19%
primary functional limitation		57%		43%
type and severity of disability, if established		67%		33%
goals and objectives for child		100%		
documentation of parent participation in IHP development		57%		43%
Medical information in records		95%		5%
Notes on parent meetings/conferences record		91%		9%

[c] Formal procedures refer to written records, procedures, or practices that take place on a scheduled, routine basis. Informal procedures are those that occur on an as-needed basis.

4.3.4 Organizational Affiliation

Overall, there were three different types of organizational affiliation among programs, none of which was dominant. As shown in Table 31, the most frequent association was with a county unit of the Association for Retarded Citizens (38% of the centers). Following closely behind were centers that were located in a United Cerebral Palsy center, a hospital, or some other rehabilitation center (35%). The remaining centers were mixed in their affiliation; for example, some were privately operated; one was a component of a school system; and another program was conducted by a religious organization. Most parents reported that their children were enrolled in the mixed organizational type(59%), with 23% enrolled in ARC facilities and 18% attending a program in a UCP center, hospital, or rehabilitation setting.

Table 31. Level of Enrollment by Organizational Affiliation
(N = 328)

	% of Parents [a]	N of Centers
Association for Retarded Citizens	23	10
United Cerebral Palsy, hospital, or rehabilitation center	18	9
Voluntary or other public service agency	59	7

[a] % of parents represents 24 centers, not the total of 26. Parent questionnaires were received from 24 centers.

4.3.5 Staffing Patterns

The program staff (as opposed to clerical and other "support" workers) of an early intervention program generally comprise two groups. The first group consists of specialists such as occupational therapists, speech therapists, or physical therapists, who may work on a part-time basis and who spend most of their time directly with children. The second group of staff members are people with a more generalist or educationally oriented background--early childhood teachers, social workers, paraprofessionals, and people in training (i.e., working toward certification). Centers are divided somewhat evenly in the proportion of these groups in their staff composition. However, the majority of parents (58%) have their child enrolled in programs in which the predominant number of staff have a "specialist/therapist" background (see Table 32).

Table 32. Level of Enrollment in Centers with Different Staffing Patterns
(N = 328)

	% of Parents	N of Centers
Emphasis on specialists/therapists	58	14
Emphasis on generalists/educators	42	12

Note: "Emphasis" was determined by examining the training and certification of each staff member within a center. A ratio of the number of staff members falling within the two categories was calculated adjusting for whether the staff member was part or full time. Centers were assigned a category according to which staffing pattern predominated. If ties occurred, the center was put in the "specialist" category; it was assumed some of the generalists/educators were utilizing specialist's skills.

Table 33. Staffing Patterns by Center

Center	Physical Therapist	Occupational Therapist	Speech Therapist/ Pathologist	Teacher	Aide	Social Worker	Psychologist	Administrator	Nurse	Physician
A	FT 2/3 T	2/3 T	FT (MA)	FT (MA)	FT	FT (MSS)	1/5 T	2/5 T (RPT)		1/5 T
B	FT	FT	FT	FT FT (no)	(2) FT (no) ½ T (BA) ¼ T (no)				1/3 T	
C		FT						1/5 T (PhD) (Psych)		as needed
D	FT	FT	FT	FT		as needed			as	needed
E	FT (no)	FT (no)	FT			FT (BA)				2/3 T
F	FT	1/3 T	1/3 T	FT		½ T				
G	(2) FT	½ T	½ T	FT (BS)	FT (AA)	FT	1/5 T	2/5 T (RPT)		1/5 T
H	FT (no)							FT (M Ed)		
I	FT	1/5 T	FT	FT (BA)	FT (AA)	FT (BA)	1/5 T	1/5 T (RPT)		1/8 T
J		½ T	½ T (MA)		(4) FT (HS)			FT (MSW)		
K	(2) FT		½ T		(10) College students		FT	FT (?)	FT	
L		FT	FT	FT		½ T (MA)				
M					(3) FT (HS)			FT (BA)	FT	
N	FT	FT	FT	¼ T (MA)	FT (BS)		1/5 T	FT (OTR)	FT	
O	1/5 T	1/5 T	2/5 T (BA) 1/5 T (MA) (2) 1/10 T	(2) FT ½ T (BA)	½ T (no)	½ T (BA)	(2) 1/10 T	FT (OTR)	½ T (BSN)	
P	FT (BS)		FT (MA)	(2) FT (BS)	(4) FT (HS)	½ T (BA)				
Q	FT	FT	FT	½ T				½ T (BS)		

Center	Physical Therapist	Occupational Therapist	Speech Therapist Pathologist	Teacher	Aide	Social Worker	Psychologist	Administrator	Nurse	Physician
R	FT	FT	FT					FT (RN)		
S	(4) 2/3 T	(3) 2/3 T	FT			FT				1/3 T
T	FT	FT	FT			FT		FT (RPT)		½ T
U	FT		FT	FT	FT (BA)	FT		FT (MA)	FT	
V	½ T		½ T	FT	FT (BA)	2/3 T (BA)		FT (MA)	2/3 T	
W				FT	FT (HS)			¼ T (MA)		
X	1/10 T	1/10 T	1/10 T	FT (BA)	FT (no)			1/3 T (MS) (speech)		
Y	FT	1/3 T	½ T (BA)	FT (BA) 1/3 T		1/3 T			FT	
Z	¼ T	1/5 T	¼ T	FT	(50) 1/5 T Volun.	1/10 T		FT (no)		1/20 T

Key to Table

- FT = full-time (e.g., 1/3 T = one-third time). Full-time means that the person works all hours during which the program is in operation. It does not necessarily mean 35 or 40 hours per week. The same principle applies to part-time workers.
- Notations in parentheses were made to describe the degree held by the staff members. In all cases, except the program administrator, notations were not used if the person held the kind of certification appropriate for that position (e.g., physical therapist who is a registered physical therapist). "(No)" means no higher education degree.
- Notations in parentheses coming before the amount of time abbreviation signifies the number of staff members falling within a particular category.
- A blank for the program administrator indicates that another staff member fills this role in addition to their primary role as a practitioner.

HS = High School
AA = Associate in Arts
BA = Bachelor of Arts
BS = Bachelor of Science
BSN = Bachelor of Science in Nursing
MA = Master of Arts
MS = Master of Science
MEd = Master of Education
MSW = Master of Social Work
MSS = Master of Social Service
PhD = Doctor of Philosophy
RPT = Registered Physical Therapist
OTR = Registered Occupational Therapist

A more specific picture of staffing patterns within each center is provided on the following page. It becomes clear that specialists/therapists are used in nearly every program. However, in some centers they are only part time workers and therefore are not part of the "core" staff. Another discernable pattern is the degree to which a program has a psychosocial component by having a psychologist or social worker as staff members. Finally, programs vary in terms of whether the program administrator performs the dual role of practitioner and administrator. In many programs, the program administrator's primary role is that of a practitioner. Very few programs have an on-site full time person responsible for program administration **per se**.

A particular intervention approach practiced in some programs may influence a center's emphasis in staff composition. It was learned through staff interviews that some centers have attempted to develop a transdisciplinary approach to intervening with the children. With this approach, staff members attempt to use a number of skills from other disciplines along with those associated with their own particular specialty. For example, an early childhood teacher might learn positioning skills from a physical therapist and then, during cognitive exercises in group play, put the child in a particular position in order to work simultaneously on gross motor skills and cognitive development. The degree to which staff members in such programs have expanded their abilities by incorporating skills from other disciplines could influence the significance of the findings regarding staffing patterns. It would be difficult, however, to measure the prevalence or value of this approach except to say that the presence of a diverse staff makes the transdisciplinary approach a realistic option.*

4.3.6 Educational Background of Program Administrators

In contrast to the pattern seen in staff composition, the majority of parents have contact with program administrators from the generalist/educator/social work group (65%). Slightly more than half of the centers had program administrators with this educational background (58%).

4.3.7 Parent Participation in the Classroom

Various patterns of parent/staff/child interactions were examined. These interactions could conceivably have an influence on the degree to which parents learn skills that can be utilized at home. An important question is whether parents in fact participate on a continuous basis within the treatment setting (i.e., usually the classroom at the center). Two-thirds (16) of the 24 centers responding involved parents directly in the intervention process during each program session while in one-third (8) of the programs, parents were typically somewhere else. In the latter group, parents may have been at the center receiving some from of parent training, attending a parent group. However, the primary thrust of parent participation was a de-emphasis on direct parent involvement in the interventions with the child at the center.

In order to develop a more precise picture of classroom participation, parents and program administrators were asked to rank four distinct forms of parent/staff/child interactions:

- Staff members engage in activities with the child while parents watch what they are doing
- Parents engage in activities with the child while staff members watch what they are doing
- Parents and staff members engage in activities with the child at the same time
- Staff members engage in activities while parents are somewhere else.

Parents were also asked to report what type of interaction they would prefer, irrespective of the types of interaction that presently take place.

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* Additional information on the concept and practices associated with use of the Transdisciplinary approach can be secured from United Cerebral Palsy (UCP), New York, New York. UCP conducted a pilot project entitled "Nationally Organized Collaborative Project to Provide Comprehensive Services for Atypical Infants and their Families" which addressed the transdisciplinary approach.

As shown in Table 34, the most frequent interaction pattern reported by program administrators was the third one--staff and parents work together at the same time (50% ranked this first). By contrast, only 22% of the parents saw this as the most frequent pattern. For parents, the most frequently cited pattern was the first one--parents observe staff members' interaction with their child (45%); however, only 23% of program administrators indicated that this was the most frequent pattern. Nearly a third of the parents reported that the most prevalent pattern was that they were somewhere else while staff worked with their child.

Overall, parents and program administrators agreed to the second most frequent interaction pattern within the classroom--parents observe staff engage in activities with their child. While parents were somewhat evenly divided as to whether this was the most prevalent or second most prevalent pattern, this seemed to be the clear second choice of program administrators.

The less frequent interaction patterns were those in which staff observe parents interacting with their child and those in which parents are somewhere else. A clear majority of both parents and program administrators ranked these two choices third and fourth respectively.

One way to view parent participation in the classroom is on a continuum from passive to active modes of interaction. Of the four modes cited previously, "parent is somewhere else" and "parent watches staff" can be regarded as more passive roles. The more active roles would be "staff watches parent" and "both work at the same time". Responses from parents within each center were analyzed to determine whether there were any trends in the data along this active-passive dimension.

The first way in which the data was analyzed was in terms of what types of parent/staff/child interactions **presently exists** according to parent. Overall, the mode of interaction receiving the highest ranking was toward the passive end of the continuum. In 12 of the 19 centers for which data could be analyzed, a majority of parents noted that one of the two passive modes predominated. A more active mode was cited by the majority of parents in 4 centers while a mixed view was given by the majority in 3 other centers.

Table 34 Staff/Parent/Child Interaction Patterns in Program

	Parent Observes Staff			Staff Observes Parent			Both Work at Same Time			Parent is Somewhere else		
Ranking	PA[a] View	Parent[b] View	Parent Wish	PA View	Parent View	Parent Wish	PA View	Parent View	Parent Wish	PA View	Parent View	Parent Wish
Ranked 1st	23%	45%	44%	5%	4%	6%	50%	22%	35%	23%	29%	14%
Ranked 2nd	63%	43%	31%	9%	21%	32%	18%	27%	31%	9%	9%	6%
Ranked 3rd	14%	10%	20%	68%	48%	41%	14%	32%	25%	5%	9%	14%
Ranked 4th	-	2%	5%	18%	27%	21%	18%	19%	9%	63%	53%	66%

[a] PA = Program Administrator N = 22

[b] N = 289 (for both view and wish columns)

A clear pattern emerged when the data was reviewed for type of parent/staff/child interaction **most preferred** by parents. In general, a trend was seen in preferences for a more active mode of parent/staff/child interaction. Parents in 10 of the 19 centers wished for a more active role in the treatment process while in 8 centers the parents wanted their role to remain the same (or the top-ranked preference was unclear). In only one center did the majority of parents want a more passive role in the center's interventions with their child. In three cases, the interpretation was made that parents wished for a more active role despite choosing a relatively passive form of interaction as their top preference (i.e., "parents watch staff"). The rationale for this judgment was that in each case, "parents are somewhere else" (the most passive role) was the predominant form of interaction at the present time. When looking at parents' preferences, there was a sharp drop in preferring to be "somewhere else" coupled with a definite increase in wishing to have a more active role of "parents watch staff." It would appear that this shift demonstrated a clear tendency to want a relatively more active role in the intervention process than currently exists.

4.3.8 Relationships Between Program Models and Other Issues

The factors associated with program models may be related to other characteristics of programs. The first relationship that was explored addressed the question of whether people of a particular socioeconomic status (SES) participated in certain program types in larger numbers than would be expected by chance. For example, do low socioeconomic status parents participate less in classroom interventions? It was found that no significant relationships existed between SES and any of the four selected aspects of program models.

A second issue addressed in analyzing the data was how diagnostic classifications might be associated with program models. Some of the four factors linked to program models demonstrated some notable findings.*

An important question is whether categorical diagnoses are related to the type of organizational affiliation. In other words, can a categorical diagnosis affect a child's participation in a particular program? One might assume, for example, that Down's Syndrome children participate more frequently in ARC centers. Likewise, children with cerebral palsy might be expected to be found most often in UCP or rehabilitation centers. The actual results do appear to support these expectations, but not as conclusively as one might assume. As shown in Table 35, a typical ARC program does have a larger proportion of children with Down's Syndrome (38%) than do the other two organizational types. The same expected pattern holds true for children with cerebral palsy. UCP centers, hospitals, and rehabilitation centers have a higher proportion of this diagnosis than the other two organizational types. However, there are also some clear similarities among the three organizational types.

There does not seem to be a significant difference among the three types of organizational affiliations with respect to children with developmental delays, mental retardation, or various neurological difficulties. In short, most diagnoses can be found within each of the three types of organizations, but some diagnoses predominate in some cases.

Another question is whether staff with a specialist orientation serve infants with particular diagnosis more often than staff with a generalist/educational orientation. Indeed, there was statistical significance (reflected in X^2, df, and confidence level) in the association between staffing pattern and diagnosis. However, this difference does not appear to be as meaningful as the statistics indicate when the data are closely examined.

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* The statistics noted in the following tables need to be viewed cautiously. Because there were so many different diagnoses, low cell frequencies resulted (i.e., less than 5 in a cell). Statistical analyses with chi-squares are unreliable when this happens.

Table 35. Relationship Between Categorical Diagnosis and Participation in Programs

(N = 296)

	ARC	UCP/Hospital/ Rehab. Center	Other Voluntary Agency
Down's Syndrome	38%[a] (24)	8% (5)	25% (43)
Cerebral Palsy	16% (10)	29% (17)	15% (26)
Developmental Delay	20% (13)	20% (12)	23% (40)
Mental Retardation	14% (9)	12% (7)	13% (23)
Spina Bifida	0	5% (3)	1% (1)
Other Orthopedic	0	7% (4)	9% (15)
Other Neurologic	6% (4)	7% (4)	3% (6)
Language/Hearing/Visual	0	0	3% (6)
Other	6% (4)	12% (7)	8% (13)
Totals	(64)	(59)	(173)

X^2 = 36, 22, df = 16, p is less than .01

[a]Figures in parentheses refer to the raw number of children. Percentage reflects the proportion of the column's total.

Table 36. Relationship Between Staffing Patterns in Centers and Diagnosis

(N = 258)

	Specialist	Generalist
Down's Syndrome	19% (32)	32% (40)
Cerebral Palsy	19% (32)	17% (21)
Developmental Delay	24% (41)	20% (24)
Mental Retardation	17% (29)	8% (10)
Spina Bifida	2% (4)	0% (0)
Other Orthopedic	7% (12)	6% (7)
Language/Hearing/Visual	1% (1)	4% (5)
Other	8% (13)	9% (11)
Totals	(151)	(107)

$X^2 = 17.9$, df = 8, p is less than .05

Note: Some diagnoses occurred on such an infrequent basis that, for clarity, they have been excluded from this table.

Table 36 shows that centers with a generalist orientation serve more Down's Syndrome children than do those with staff who are predominantly specialists or therapists (32% to 19%). However, in most of the other diagnostic categories, there is a higher proportion of children in the specialist oriented centers. Nevertheless, the actual overall differences in proportion are reasonably small.

An additional issue is the relationship between the functional difficulties of children and program models. Developmental quotients in the four developmental areas showed very few significant relationships when compared to the four aspects of program models. The functional capabilities of children served by centers with a specialist/therapist orientation were not different from those of children participating in centers with a generalist/educationally oriented staff. Furthermore, there were no real differences in the functional capabilities of children in centers emphasizing parent classroom participation when compared to children in centers where parents were not directly involved in the classroom.

A significant relationship was established when examining functional difficulties across organizational affiliations. With respect to gross motor skills, UCP programs tended to have children with more serious impairments than did ARC or other voluntary agencies. ARC programs had lower functioning children in the gross motor area than did the "other voluntary agency" type of organization. These relationships are shown in Table 37. In each of the other functional capabilities areas no differences were found among the three organizational types.

Table 37. Relationship Between Type of Organizational Affiliation and Gross Motor Skills of Children

	ARC	UCP Hospital/ Rehab. Center	Other Voluntary Agency
low (0 to .25)	25% (11)	37% (17)	24% (35)
low-middle (.26 to .49)	48% (21)	50% (23)	36% (53)
middle-high (.50 to .74)	20% (9)	9% (4)	29% (42)
high (.75 to 1.0)	7% (3)	4% (2)	11% (17)
Totals	(44)	(46)	(147)

$X^2 = 13.06$, df = 6, p is equal to or less than .05

Note: In all tables indicating functional skills in four intervals as presented above, the same score ranges will be used as noted in the parentheses above.

The fourth aspect of program models--the program administrator's educational orientation--showed one significant relationship with the functional capabilities of children. Program administrators with a specialist/therapist orientation tended to have lower functioning children in the gross motor area than did administrators with a generalist/educational/social work background. No significant relationships were established in the other three developmental areas.

4.3.9 Forms of Parent Participation

In section 4.3.3, centers were characterized by whether parents were directly involved in classroom interventions. This form of participation is one of a number of ways in which parents take part in their child's treatment. Parents and program administrators were asked whether various types of parent participation existed within their center. They were not asked how frequently each type took place, but simply whether the particular activity existed. As shown in Table 39, the highest proportion of both parents and staff reported two forms of parent participation as occurring most frequently:

- meetings and discussions with treatment staff to share information about their child
- participation in the child's treatment at the center

The majority of parents reported that the following types of participation were at least available to them:

- parent discussion groups
- home visits by staff
- individual counseling sessions

There were four types of participation that did not exist, according to the majority of parents:

- parent organization
- fund-raising activities
- outreach to community groups or individuals
- family days or nights

These same activities had the lowest frequencies for program administrators.

Two issues need to be carefully considered in drawing any implications from these results. First, parents and program administrators were merely asked whether these forms of participation existed. They were not asked about the degree to which people actually use services. In fact, during the group interviews, program administrators revealed that typically there was a core group of parents who were involved in just about all forms of parent activities but that this group did not necessarily represent a majority of parents. One of the staff's major tasks was to reach the parents who were not among the core group. Second, there was a high degree of variation among the parents in each center regarding whether or not the form of participation existed. In a number of cases, parents within a given center were approximately evenly divided between "yeses" and "nos" for many of the types of parent involvement. In short, parents within centers held different perceptions as to what constituted the parent participation program for that center.

4.3.10 Congruence Between Staff and Parent Views of the Child

An important characteristic of programs is the sharing of information between staff and parents regarding the developmental skills of the child. One way to describe a critical element of this communication process is to examine whether parents and staff share similar views as to the child's developmental quotient. One would assume that congruent views are desirable since staff and parents could share a common framework on particular objectives with the child.

In all four developmental areas there was a reasonably high degree of agreement between parents and staff; nearly half of the parents gave the same developmental quotient for their child as did staff members, and in three of the four functional areas a majority of parents rated their child within .10 of staff rating.

If one examines the Pearson Product Moment correlation coefficients of the four areas, the highest proportion of agreement between parents and staff appears to be in the gross motor area ($r = .77$). The fine motor area demonstrates the next highest level of agreement ($r = .64$), followed by language and social/personal skills respectively.

Overall, when there was at least some difference between the views of the parents and staff, parents tended to see their child as functioning better than did the staff members. In all four areas, 33%-41% of the parents perceived their child to be on higher developmental level than did the staff member. Approximately one of every five, however, judged their child to be functioning with greater limitation than did the staff (see Table 40).

The results indicate that there were two groups of parents; one group whose views of their child were similar to those of the staff; a second group who demonstrated a reasonably high degree of difference from the views of staff members. (This is reflected in the high standard deviations.) Among parents and staff who did not agree, there was a large range of values.

Table 38. Relationship Between Gross Motor Skills of Children and Program Administrator's Educational Orientation

(N = 237)

Gross Motor Skills	Specialist/ Therapist	Generalist/ Educator/ Social Worker
low	35% (30)	22% (33)
low-middle	42% (36)	40% (61)
middle-high	13% (11)	29% (44)
high	9% (8)	9% (14)
Totals	(85)	(152)

$X^2 = 9.87$, df = 3, p is less than .02

Table 39. Types of Parent Participation from Both Parents' and Program Administrators' Points of View

	Parents			Program Administrators		
	N	Yes	No	N	Yes	No
Meetings and discussions with the treatment staff to share information about their child	313	93%	7%	26	96%	4%
Parent discussion groups	307	69%	31%	26	88%	12%
Individual counseling with a social worker or psychologist	308	61%	39%	26	88%	12%
Participation in their child's treatment at the center	312	85%	15%	26	96%	4%
Home visits by staff from the program	315	65%	35%	26	88%	12%
A parent organization	299	43%	57%	26	54%	46%
Fund-raising activities	303	47%	53%	26	50%	50%
Outreach to community groups or individuals	288	32%	68%	26	58%	42%
Family days or family nights	300	37%	63%	26	54%	46%

Table 40. Differences Between Parent and Staff Assessments of Functional Capabilities of Children

	Gross Motor N = 289	Fine Motor N = 284	Language N = 292	Social/ Personal N = 278
Parents higher than staff	33%	39%	41%	35%
Same	48%	41%	42%	43%
Parents lower than staff	19%	20%	17%	22%
Percentage +/− .10 of same	57%	49%	51%	54%
Percentage +/− .05 of same	51%	44%	47%	49%
Mean difference [a]	−.05	−.09	−.09	−.05
Standard Deviation	.23	.26	.27	.30
Correlation between parents and staff [b]	.77	.64	.57	.53

[a] These mean scores and standard deviation figures refer to the raw data--the developmental quotients. The difference scores were obtained by subtracting the parent's quotient from the staff's quotient. Therefore, the range of these difference scores is between −1.00 to +1.00. The negative difference scores mean that parents have given their child a higher developmental quotient than did the staff.

[b] All correlations were significant at the p is less than .001 level.

4.3.11 Relationship Between Diagnoses and Functional Capabilities

It is often assumed that the organizational affiliation of a center is an important factor in the center's program. Accordingly, most children are referred to ARC centers if their difficulties are associated with some form of mental retardation on the assumption that children diagnosed as having mental retardation have similar program needs. A related assumption is that children with similar diagnoses have similar functional capabilities. The data were explored to determine whether this hypotheses is reasonable.*

Among the most frequently cited diagnoses, there was relatively little difference in the **average** developmental quotients for Down's Syndrome, cerebral palsy, mental retardation, and developmental delay. However, children with Down's Syndrome appeared to function at a slightly higher level than the other three types of children. As shown in Table 41, children with spina bifida or language/hearing/visual impairment had much higher developmental quotients than those in other categories. The children with spina bifida, however, were rated relatively low in gross motor skills ($\overline{X}$ = .38). In three of the four developmental areas, children with cerebral palsy typically were rated lower than the other three major groups.

These patterns, however, based on analyzing the means, tend to obscure the differences **within** each diagnostic category. In each of these three major diagnoses, variation exists in all four developmental areas. Children fluctuate so greatly, even within a single diagnostic category, that attempting to identify systematic differences in the functional capabilities among various diagnoses may lead to invalid conclusions.

* Developmental quotients based on staff members' completion of the FAF were used for this analysis.

Table 41. Relationship Between Diagnosis and *Functional Capabilities*

Diagnosis	Overall Mean	Gross Motor Mean	Fine Motor Mean	Language Mean	Social/ Personal Mean[a]
Down's Syndrome (N = 68)	.55	.48	.61	.52	.57
Cerebral Palsy (N = 46)	.42	.32	.41	.46	.48
Developmental Delay (N = 57)	.52	.52	.55	.50	.52
Mental Retardation (N = 38)	.50	.49	.52	.49	.48
Spina Bifida (N = 4)	.69	.38	.81	.81	.75
Other Orthopedic (N = 19)	.57	.39	.57	.66	.64
Other Neurologic (N = 11)	.43	.35	.48	.42	.46
Language/Hearing/ Visual (N = 5)	.77	.77	.77	.78	.77
Other (N = 22)	.43	.34	.49	.48	.42

[a] the number within each diagnostic category varied slightly in the Social/personal area due to missing data.

Note: Mean developmental quotients based on staff members' completion of FAF.

4.3.12 Re-evaluation of Children

As indicated above, programs' evaluation includes, at a minimum short-range goals and objectives on IHPs for each child. The programs review these goals at various points during the year and create new ones, depending on the developmental progress of the child. As shown in Table 42, the most frequently cited rate of review is four times a year (46% of the centers). A sizable minority of programs re-evaluate the children even more frequently than this--once a month (31%). Overall, almost 90% of the programs conduct a goals/objectives review four or more times a year.

Table 42. Frequency of Goals/Objectives Review

Once a month	6 times a year	4 times a year	2 times a year
31%	11.5%	46%	11.5%
(8)	(3)	(12)	(3)

Both parents and staff members were asked about the other's willingness to participate in a review session. An overwhelming majority from each group described the other as being very willing to participate in such a review (approximately 85% for each group). Only one program administrator perceived the parents as less than enthusiastic about re-evaluating the child's goals/objectives. Likewise, few parents (5%) judged staff as either slightly or not willing to do this (see Table 43).

Table 43. Willingness of Parents and Staff to Discuss Goals and Objectives

	Very Willing	Moderately Willing	Slightly Willing	Not Very Willing
Program Administrators' Views of Parents (N = 26)	85%	11%	4%	0
Parents' Views of Staff (N = 314)	86%	9%	3%	2%

Another important consideration in the re-evaluation process is how parents participate in the review. According to program administrators, centers use four different methods when conducting the goals/objectives review (see Table 44). However, the majority of centers use one of two methods. The most frequent method is that staff members first meet with parents to discuss the child's progress relative to current objectives, and then write the new objectives without the parent being present (42% of the centers). The next most frequent method is for the staff as a group to review the child's progress relative to current objectives, then write new objectives, and subsequently share these with parents (39% of the centers). Only one center does not involve parents in some manner during the re-evaluation process.

Table 44. Method of Parent Participation in Goals/Objectives Review

(N = 26)

a = Parents and staff discuss the child's progress relative to current objectives. Then new or revised objectives are written by parents and staff together.

b = Parents and staff discuss the child's progress relative to current objectives. Then the staff writes new objectives without the parents being present.

c = Staff reviews the child's progress relative to current objectives, writes new or revised objectives, and later discusses the changes with the parents.

d = Staff reviews the child's progress relative to current objectives. Then the staff writes new or revised objectives but does not share them with parents.

a	b	c	d
15%	42%	39%	4%
(4)	(11)	(10)	(1)

4.3.13 Summary

Eleven different funding sources provide some portion of the budget of early intervention programs. Typically, more than one funding source is utilized by a program. The most common source of financial support are parents (fees for services), Developmental Disabilities Council grants, Special Child Health Services grants and Title XX funds.

The most frequently used mode of monitoring and evaluation at the centers is accountability to a board of directors. An almost universal element of the monitoring and evaluation procedures is the individual habilitation plan (IHP). Other elements found relatively often are written statements of the program's philosophy and purpose, goals and objectives, and policies and procedures. Formal staff evaluation is used in all but one of the centers, and this usually includes a written staff evaluation instrument. Most programs do attempt to gather feedback from parents. Approximately one out of five programs receive no evaluative feedback from external sources.

Since no typology of program models exists for early intervention programs, four characteristics that influence services were designated for this study:

- type of organizational affiliation
- staffing patterns
- parent participation within the classroom
- educational background of program administrators

The three types of organizational affiliation found among programs were regional chapters of the Association for Retarded Citizens (ARC), local United Cerebral Palsy (UCP) centers, hospitals or rehabilitation centers, and voluntary or other public service agencies. The majority of parents receive services from centers run by voluntary or other public service agencies (e.g., school systems).

Staff at centers are generally either specialists or generalist/education people. Specialists include occupational therapists, speech therapists, and physical therapists; generalists/educators include teachers, social workers, and paraprofessionals. The majority of children are enrolled in programs staffed by specialists and administered by generalists.

With respect to parent participation in program sessions, program administrators perceived parents as participating primarily in simultaneous staff-parent interaction with the child; parents, on the other hand most frequently described their involvement as mainly observing while staff members conducted activities with the child.

The characteristics that influence services were compared with other aspects of programs, with the following results:

- Diagnostic classifications are associated with staffing patterns and type of organizational affiliation. More children with Down's Syndrome and with language/hearing/visual difficulties are served in centers with generalist oriented staff. In addition, as might be expected, children with Down's Syndrome participate more frequently in ARC centers, and those with cerebral palsy participate more often in UCP or rehabilitation centers.
- Functional difficulties of children are associated with organizational affiliations. In the area of gross motor skills, UCP programs tend to have children with more serious impairments.
- Program administrators with a specialist orientation tend to have children in their programs who are functioning at a lower level in the area of gross motor skills, than those of administrators with a generalist orientation.

With respect to parental participation, a wide variety of activities were identified by parents and staff Meetings and participation in treatment at the center were identified most often as desirable activities.

Staff and parents tended to agree when assessing a particular child's present functioning. When there was disagreement, parents tended to rate their child at higher functioning levels than did staff.

With respect to the relationship between diagnosis and functional capabilities, it was found that children who could not be grouped into specific diagnostic categories tended to have lower developmental quotients than others. Also, children diagnosed as having spina bifida or language/hearing/visual impairments had higher developmental quotients than others.

Finally, goals and objectives for all children were reported to be reviewed at least quarterly at 90% of the centers.

4.4 Perceived Outcomes of Programs

An objective and systematic measurement of the results of early intervention programs was beyond the scope of this report. Identifying direct benefits of the programs would require a carefully controlled experimental design and might include a longitudinal assessment of children. Nevertheless, parent satisfaction together with perceptions of results by both parents and staff can provide an important starting point in evaluating the outcomes of programs.

In both the Parent Questionnaire and the group interviews, parents offered judgments on a number of areas regarding the functioning of programs. They also assessed the outlook for their own child's future. These assessments can be compared with staff projections for each child.

4.4.1 Parent Satisfaction

Parents were asked whether their child was receiving particular forms of assistance and, if so, the degree to which they found this assistance to be helpful. As shown in Table 45, the most children were being helped in the areas of gross motor and fine motor coordination (88% and 91% respectively). Assistance was also being provided to a great many children in receptive language (84%). Feeding skills, which many staff members indicated are critical for future language development, were part of the treatment for nearly three-quarters of the children. Somewhat fewer, but still a majority of the children, were receiving assistance in three other areas of development: expressive language, cognitive skills, and social skills. The one area in which fewer than half of the children were receiving assistance was toileting skills (19%).

The majority of parents found the assistance "very helpful" in three-quarters of the categories.

Table 45. Helpfulness of Various Types of Assistance Given to the Child

Type of Assistance	Receiving Assistance			If yes, how helpful is this assistance?				
	N	Yes	No	N	Not Very	Slightly	Mod-erately	Very
Understanding what is said to him/her	307	84%	16%	251	3%	10%	31%	56%
Expressing him/herself through words	306	61%	39%	180	9%	15%	27%	49%
Toileting skills	307	19%	81%	52	4%	27%	35%	35%
Feeding skills	310	73%	27%	220	4%	13%	25%	58%
Physical skills like walking or sitting	313	88%	12%	272	1%	11%	17%	71%
Hand coordination skills like holding a glass	315	91%	9%	281	2%	7%	20%	71%
Cognitive skills like recognizing objects in pictures	308	69%	31%	206	3%	11%	27%	59%
Social skills like playing a game with other children	308	61%	39%	185	1%	15%	27%	57%

Only in the areas of "expression through words" and "toileting skills" did less than half of the parents not rank the assistance as very helpful.

In the Parent Questionnaire, parents responded to a number of questions related to their satisfaction. For the purpose of data analysis the questions have been grouped into five categories as follows:*

- satisfaction with the forms of assistance being given the child
- satisfaction with the forms of parent involvement offered
- satisfaction with assistance received in family life issues
- satisfaction with ways information about the child is shared
- satisfaction with assistance on what to do with the child at home

In four of the five groupings, a substantial majority of parents were highly satisfied with what they found in programs. Parents were most satisfied with how information about the child is shared by staff members (see Table 46).

In contrast to the other groupings, only one of every four parents were highly satisfied with how programs helped them in family life issues. The majority judged this assistance to be of low to medium quality. It should be noted, however, that a relatively low number of people responded to the family life questions (N = 189). Many parents (almost 40%) circled "doesn't apply" for these questions.

* The five categories of parent satisfaction were obtained by topically grouping various related items in the parent questionnaire. Independence among these five categories cannot be assumed; conceptually, the categories may overlap to some degree.

Table 46. Parent Satisfaction Analyzed in Different Categories

	N	Low[a]	Medium[a]	High[a]
Satisfaction with the forms of assistance being given to child	302	2%	17%	81%
Satisfaction with forms of parent involvement offered	313	4%	16%	80%
Satisfaction with assistance received in family life issues	189	25%	49%	26%
Satisfaction with how information about child is shared	325	2%	10%	88%
Satisfaction with assistance on what to do with the child at home	325	5%	15%	80%
Average		7%	21%	72%

[a] Degree of satisfaction is based on the numbers in scales of the Parent Questionnaire. "Low" refers to a range of 1.0 to 1.9 when all items in this category were averaged. "Medium" refers to a range of 2.0 to 2.9, and "high" to a range of 3.0 to 4.0.

Of those responding to the "best aspects of programs" question on the Parent Questionnaire, parent involvement was the most frequently cited positive feature (see Table 47). The "child's therapy" and "improvement" were also mentioned. A sizable number of comments pointed to the caring attitude and professionalism demonstrated by staff as a positive element of the program.

Table 47. Best Aspects of Programs: Parent's View

	N[a]	% Mentioned
Parent involvement	78	18
Child's therapy	74	17
Child's improvement	42	10
Caring attitude of staff	42	10
Professionalism of staff	31	7
Socialization experience for child	28	6
Overall support given to parents	28	6
Individual attention given to child	26	6
Overall good program	18	4
Parent discussion groups	18	4
Home visits	16	4
Existence of the program	12	3
Other	22	5

[a] The numbers in the "N" column refer to how many times this aspect of the program was noted in the Parent Questionnaire. Parents could write down more than one comment.

Table 48. Negative Aspects of Programs: Parent's View

	N[a]	% Mentioned
No bad aspects	56	18
Program meets too infrequently	42	13
Shortage of staff	34	11
Problems with frequency or nature of therapy	28	9
Center is too far away	22	7
How children are grouped (e.g., includes all disabilities in one group)	17	5
Lack of concrete information from staff	14	4
Parent program	13	4
Insufficient parent participation	11	3
Lack of progress by child	10	3
Structure of the program sessions	8	3
Not enough space	7	3
No/poorly run parent group	6	2
Other	45	14

[a] The numbers in the "N" column refer to how many times this aspect of the program was noted in the Parent Questionnaire. Parents could write down more than one comment. Two hundred thirty seven parents offered a total of 313 comments about negative aspects of programs.

In the group interviews, parents provided a number of additional details regarding the positive aspects of the program. (For a complete listing of positive comments, see Appendix H.)

A number of parents made comments about the caring and flexible attitudes of staff members. These qualities appear to promote a higher level of motivation in parents to help their child. According to parents, staff also serve as important models regarding disciplining of children; many parents tend to be "softer" with their children than they should be and the firmness of staff helps them to see that the child is indeed capable of new behaviors.

Parents also commended the programs for their help in dealing with a variety of problems -- child-centered, marital, and other. This help was not restricted to program hours. Many staff gave out their home phone numbers to parents so that assistance could be provided immediately when needed.

Also mentioned frequently was the coordinating or facilitating function of program staff. Contacts with doctors, explanations of legal rights, and assistance with preschool placement were included in this category.

When parents were asked to record their opinions of the "negative" aspects of the programs, many wrote nothing. Of those who wrote something, the largest number (18%) actually wrote "no bad aspects" (see Table 48). Of those who mentioned a negative aspect, the most frequently cited problem was that the program "meets too infrequently". Shortage of staff, problems with the frequency or nature of the therapy, and location of the center were other relatively common concerns of parents.

Parents were also asked about what they thought needed to be improved in the programs. In the results obtained through the Parent Questionnaire, as shown in Table 49, the most frequently cited need was for the program to meet more often and/or for a longer period of time (20% of improvements mentioned). However, the number of parents who expressed this view were nowhere near a majority. In another part of the questionnaire, 89% of the parents expressed the view that the length of each program session was "just about right"; only 10% wished it were either longer or shorter. Concerning the number of sessions per week, 62% were satisfied with the existing number; 37% did want more sessions per week. Also frequently noted were the desires to have more staff, to have more structure in the parent groups, and to have more information about children.

Table 49. Needed Improvements in Programs: Parent's View

	N[a]	% Mentioned
Meet more frequently and/or longer	61	24
More staff	49	20
More structure to the parent groups	23	9
More information about child	21	9
Different forms of parent participation	20	8
New equipment for therapy	14	6
More individual work with child	9	4
More physical therapy	9	4
More space	9	4
Better transportation options or new location	9	4
Variations needed in child's therapy	9	4
Greater understanding of parent by staff	7	3
Home visits - have more or start them	7	3
Meet on different days	4	1
More participation by fathers	4	1

[a] The numbers in the "N" column refer to how many times this aspect of the program was noted in the Parent Questionnaire. One hundred ninety parents offered a total of 246 comments about needed improvements in programs.

Similar suggestions for improvements surfaced during the group interviews, but with additional details provided. Not only was more staff an issue, but also maintaining the same staff was a needed improvement noted by a number of parents. (The specific improvements noted in the group interviews appear in Appendix I). In regard to increasing the number of sessions for their child, a few parents suggested that children should be seen more often when beginning the program; others indicated that they would like to see more sessions offered if their child is not showing much improvement during a particular period of time.

A number of parents disapproved of the waiting period prior to enrollment in the program. They felt that programs should eliminate waiting lists.

Many parents made comments about the fact that few fathers participate in the program. While reasons were offered to explain this situation, it was suggested that more needs to be done to attract fathers to the programs, such as creating father groups to meet at night or holding evening sessions with all parents.

While not directly related to the early intervention program, parents expressed a number of general concerns about the problems they have encountered as parents of children with developmental disabilities. These problems include the following:

- prohibitive costs of all necessary services for the child
- low eligibility requirements for SSI
- lack of standards or accreditation of programs
- lack of publicity about programs
- lack of central listing
- lack of knowledge on the part of physicians about programs, appropriate treatments, or appropriate referrals
- lack of public awareness about specific disabilities

4.4.2 Staff Views on Positive Aspects and Needed Improvements in Program

During the group interviews, staff were also asked about the strengths of their particular programs. Two responses were mentioned most frequently. First, staff described the teamwork and support from other staff that they experienced on a daily basis. Second, they spoke highly of the programs' focus on training the parent in skills that can be performed at home; staff supported the programs' position that parents need to understand how the child can be helped by making modifications in present home resources, that the family's whole life does not need to be restructured. (For a complete list of positive staff comments see Appendix J.)

Table 50. Gaps in Service Described by Program Administrators

	Number of Times Mentioned[a]
Lack of funding in some area(s)	11
Lack of parent involvement	7
Staffing problems and turnover	7
Inadequate staff/client ratio	6
Need of parent-centered group for support, education, etc.	5
Insufficient programming for children	5
Lack of support services at other agencies	4
Lack of time for parent conferences	3
Inadequate transportation of child/parents to center	3
Home visits infrequent or lacking	3
Lack of complete medical evaluation	3
Insufficient working space	2
Lack of communication with other programs	1
Need for transdisciplinary approach	1
Need for updated record-keeping	1

[a] 26 program administrators provided data on this question.

During the group interviews, program staff offered additional ways in which they thought their programs could be improved. In a number of cases, funding was the first thing mentioned. Staff thought that their unreasonably low salaries contributed to turnover. The overall opinion was that most of the programs' difficulties could be remedied by more funding (e.g., a psychologist could be hired, a home visiting program could be added.) Overall, staff thought that they did not have enough time to perform all of the tasks that were necessary to do a thorough job; they needed more time to plan, to work directly with the children, or to conduct meetings related to special cases.

Program staff also reported that referrals were needed. A number of comments were made about lack of support from the medical community and general lack of knowledge about early intervention programs.

Frequently noted as needing improvement were the physical settings of programs. Staff remarked that more space was needed to be able to work with children individually on particular tasks. (For a complete listing of staff suggested improvements, see Appendix K.)

Program staff also described components of their programs that they would like to see strengthened. In particular, program administrators outlined gaps in the services provided. Lack of funding for a variety of program improvements was the difficulty most frequently noted. A number of administrators indicated that low parent involvement, staffing problems and turnover, and inadequate numbers of staff were also problems (see Table 50).

Staff presented other concerns during the group interviews that were not necessarily associated with the functioning of their programs. These issues, some of which were also mentioned by parents, were as follows:

- lack of federal responsibility for providing early intervention services to infants
- Need to publicize the fact that increased funding for early intervention programs may raise a child's functioning level and therefore be cost-beneficial in the long run
- lack of clarity on how programs will secure additional funding when grants expire
- poor financial coverage for parents
- lack of formal representation of early intervention programs on the New Jersey Developmental Disabilities Council
- poor communication with the Special Child Health Services regarding funding--particularly with respect to the requirement that the etiology of a child's disability must be biologically based

4.4.3 Results of Programs

Parents were asked in the group interviews what they thought were the actual accomplishments of the program--that is, not what they hoped would happen but what they could point to as a definite result of the program for their child, for the parents themselves, for other family members, or for the community at large.

Parents offered relatively consistent responses. The two results most frequently mentioned related to developmental milestones attained by children and emotional support for parents. With respect to the milestones, parents cited examples such as a child's gaining the ability to swallow contrary to a doctor's prediction. In general, documented improvements were in the area of gross motor skills.

With respect to emotional support, parents described how the program gave them a place to vent and share feelings of anger, disappointment, and/or depression. As one parent pointed out, "Even if children don't really benefit from the program, it saves the sanity of parents." This type of support resulted in the development of a more positive attitude towards their child, manifested by behaviors such as taking their child on shopping trips and for walks in the neighborhood.

Yet another important result frequently noted by parents was their ability to manage the child at home. Skills related to restructuring the physical setup at home, playing with the child in ways to expand the child's muscle tone, and promoting pre-speech skills, were offered. (For a listing of all points made by parents describing the actual results of participation in the program, see Appendix L.)

Staff perceptions of what the programs actually accomplish covered a wider range of issues in somewhat greater detail than the parents' perceptions. The programs were described by staff members as having a preventive function: a child may not progress much in actual development, but maintenance of existing skills could be a major accomplishment. Some staff thought that dramatic changes in the whole physical make-up of children with Down's Syndrome were being accomplished--less hunched posture, less shuffle in their gait, and less tongue dangling. One center indicated that many of their graduates with mental retardation tested as "educable" as opposed to "trainable".

Program staff also described attitude changes seen in parents. A closer parent-child bond was evident as well as a greater overall sense of well-being in the parent. Staff noted that much of the support given to parents was from other parents, not necessarily from program personnel.

Despite the difficulties staff had noted previously regarding professional and community awareness, there was a feeling that the community has begun to be aware of the existence of early intervention programs. Several staff members described a "domino effect": Parents who have "graduated" from early intervention programs, have been educated about their rights and have seen quality services; when their children enter pre-school classes, these same parents tend to demand (and receive) improved services. (The specific results identified by staff can be found in Appendix M.)

4.4.4 Projections of Future Services Needed

In the Parent Questionnaire, parents were asked to predict what services their child would need 5-10 years from now. A number of parents were not able to respond to this question; 45% did not know what their child would need and, therefore, did not fill out any answers. Three percent did not think that their child would need any services by that time. Of those who were able or willing to speculate about the future, speech therapy was the most frequently cited service (91%), followed closely by the need for special classes and physical/occupational therapy (see Table 51). Relatively few parents thought that a residential school would be necessary in the future (25%), and an even smaller proportion thought that special living arrangements outside the home would be required (10%).

Table 51. Projections by Parents about Services Needed in 5-10 Years

(N = 175)

	Yes	No
Speech therapy	91%	9%
Physical/occupational therapy	87%	13%
Special classes	87%	13%
Health/medical services	82%	18%
Special recreational or leisure time activity programs	75%	25%
Special transportation arrangement	70%	30%
Pre-vocational training	47%	53%
Psychological counseling or guidance	36%	64%
Special residential school	25%	75%
Special living arrangements outside the home	10%	90%

4.4.5 Expectations for Future Functional Capabilities

In addition to being asked their views about the child's current functioning (see section 4.3.6), both parents and staff were asked to make an additional judgment regarding the functional capabilities anticipated when the child reached the age of 3. A number of parents either were unable to make this projection or gave incomplete data; 62% were able to represent their expectations for the child's future functional level.

A notable difference was found when comparing the level of agreement on the child's current functioning and the level obtained on the child's future functioning. In three of the four developmental areas, parents and staff demonstrated more disagreement regarding the child's future functional capabilities than regarding present functioning. In fact, as shown in Table 52, the area with the highest level of congruence for current functioning (gross motor abilities, .77) had the lowest degree of congruence for future functioning (.34).

Table 52. Congruence Between Parent and Staff Evaluations of the Child: Present and Future Functioning

	Present	3 Years Old
Gross Motor	.77	.34
Fine Motor	.64	.56
Language	.57	.59
Social/personal	.53	.47

All correlations were significant at the p is less than .001 level.

Table 53. Correlation Between Perceptions of Child's Present and Future (Age 3) Functional Capabilities: Parents and Staff

	Parents	Staff
Gross Motor	.51[a]	.39
Fine Motor	.39	.38
Language	.38	.42
Personal/social	.27	.39
Average r	.39	.39

[a] All correlations were significant at the p is less than .001 level.

Further analysis was conducted on the amount of change expected by parents and staff in the child's future functional capabilities. Correlations were calculated to describe the relationship between a parent's present and future view of his/her child. The same correlation was done for staff. The higher the correlation, the more similar are the views of present and future functioning. This would imply that the lower the correlation, the higher the expectations for change; the same average correlation of .39 was obtained for each group. Two interesting differences appeared, however. Staff seemed to hold a more optimistic outlook for the child than did the parent in the area of gross motor skills; the correlation between present and future functional capabilities was .39 for staff and .51 for parents. On the other hand, staff typically held less optimistic outlooks than parents in the personal/social area.

4.4.6 Summary

Both parents and staff were able to identify a number of areas where programs were producing clear benefits. Most parents were highly satisfied with most aspects of the programs. Flexibility of programs in meeting the special needs of parents and the support parents received from other parents were mentioned most often as concrete benefits. Parents seemed to be least satisfied with the help programs offered related to family issues, such as marital interaction; however, many parents did not regard family life issues as a concern.

When staff and parents pointed to the specific accomplishments of programs, they most often noted the following:

- developmental milestones achieved by the child
- greater acceptance and knowledge on the part of parents regarding their child's difficulties
- increased ability of parents to help their child at home
- qualitative changes, particularly in the gross motor area
- increased number and improved quality of preschool programs in the community

Overall, parents and staff shared relatively similar views regarding the child's present functional capabilities. The study findings did not support the assumption that parents are typically more optimistic than staff (sometimes interpreted as "unrealistic") regarding their child's future development.

Both staff and parents offered a number of suggestions for programs improvement, including the following:

- more program sessions or longer sessions
- additional full-time staff and less staff turnover
- increased involvement of fathers
- improvement in the level of parent involvement and the structure of parent participation
- greater support and coordination from government agencies

5.0 CONCLUSIONS

The following conclusions serve to highlight inferences that are suggested by the data in each of the major findings sections.

5.1 Characteristics of the Service Population

- The early intervention programs serve a relatively wide cross-section of the general population.

There does not seem to be an overconcentration of wealthy, well-educated, or Caucasian individuals or those from minority groups or of low socioeconomic status. Programs do serve slightly more individuals at the lower ends of the educational, occupational, and income scales than at the higher ends.

- Socioeconomic status does not appear to be very influential in a parent's selection of or a child's referral to a particular type of program.

When program models were examined, none of the four aspects of program models demonstrated a significant relationship to socioeconomic status. (This is not to say that specific programs do not, by virtue of such factors as location, provide services to specific population groups.)

- Young parents, particularly teen-age parents, may be underrepresented in early intervention programs.

This is particularly noteworthy in view of the observation by some that developmental disabilities tend to be more common in the children of young parents.

- A sizable proportion of parents who are not on Medicaid or receiving Supplemental Security Income experience financial hardship in affording services for their child.
- Overall, children participating in programs are functioning at approximately 50% of their age-appropriate skill levels.

The only exception to this generalization is in the area of gross motor skills, where children are, on the average, functioning at a somewhat lower level.

- Programs appear to serve a preventive as well as habilitative function.

With developmental delay being the second most frequent diagnosis, the programs are serving children who may or may not ultimately become developmentally disabled.

5.2 Entering Programs

- It is not clear whether programs are meeting the demand for existing services, partly because the size of the demand is indeterminant. It does appear that a number of children needing services are not enrolled in early intervention programs.

The 2% prevalence rate (i.e., 6,000 children) tends to overinflate the actual number of children in New Jersey whose parents may feel a need for services, because it is based on observation of an older group whose functional limitations are more easily identifiable. Also, referrals to early intervention programs may be low due to the even greater difficulties of identifying disabilities prior to age 2. Furthermore, the 2% rate assumes that if all 6,000 children could be identified, they should all be enrolled in a program. However, this is not a correct assumption. The decision by parents to enroll their child in a program is highly complex and is influenced by many factors, including the readiness and capacity of parents to spend the time in transporting their children and the acceptability of staff attitudes and activities.

- Although doctors generally inform parents about resources for their child, parents have a difficult time in initially learning about the existence of programs.

Once a parent does know about a program, a relatively short amount of time typically passes before the child actually begins participating in the program.

- Problems with transporting children to programs can affect program participation.
- Parents seem to be pleased with the programs' handling of the intake process. Although no promises for developmental progress are made, parents often became optimistic upon seeing the support that a program can provide.

5.3 Characteristics of Programs

- Programs operating under Council grants appear to be highly dependent on council funding. In general, the income that programs are able to generate from all sources appears to be a limitation to program improvements.
- While a number of procedures are employed to ensure program quality, few standardized monitoring and evaluation procedures exist.

Many programs are not licensed. Those that are licensed are assessed by the two state agencies that administer grants. Most programs do not have a program evaluation plan that could provide supportive documentation of program effectiveness.

- The patterns of program characteristics used as variables (organizational affiliation, staff orientation, administrative orientation, parent participation) did not appear to have much bearing on levels of enrollment.
- Diagnostic classifications do not appear to be a sufficient predictor of a child's functional capabilities.
- In many cases, the mere presence of a parent at the treatment center does not maximize the utilization of parents in the treatment process. A more active role seems to be a goal of the majority of parents. This would involve parents in a more direct hands-on approach with their child.

Within each diagnostic category, the functional skills of children varied greatly. While some differences based on diagnoses could be found, there were also a number of similarities in the functional skills of children with different diagnoses.

- Overall, parents and staff share reasonably similar views of a child's functional capabilities, particularly in the gross motor area.

5.4 Perceived Outcomes of Programs

- In general, parents seem to be satisfied with many aspects of the programs.
- Family life issues were identified by many as a concern. Programs need to strengthen the assistance offered to parents in this area.
- Staff may not be communicating clearly to parents the forms of participation that are available to them in the program. Staff may need to present these options to parents a number of times.

This conclusion is based on the discrepancies noted within centers regarding the reported forms of parent participation. While some distortion is always part of the perceptual process, the differences among parents were too large to be explained by perceptual distortion alone.

- Parents and staff provided concrete examples of results presumed due to program intervention. These results were not limited to developmental changes in the child but included a clear impact on parents themselves, on marital relationships, on siblings, on extended family members such as grandparents, on the community, and on professionals.

Future research that attempts to document the effectiveness of early intervention programs should pay particular attention to impact indicators. Changes in children may be too narrow a scope for an assessment of the benefits of early intervention programs.

- Most parents feel reasonably confident of their ability and/or willingness to manage their child at home in 5-10 years.

A relatively low proportion of parents indicated that some residential arrangement outside the home would be needed in the future.

- When parents predictions about the child's functional capabilities at the age of 3 are compared with those of staff, a reasonably high degree of congruence is evident.

5.5 Summary

In general, a network of early intervention programs exists throughout the state and provides a valuable service to parents. The benefits seem to reach beyond the children in the programs. Nevertheless, improvements can be made to strengthen the programs. Both staff and parents have indicated a number of areas in which changes are needed. Some of the changes would require additional funds; a number could be accomplished by restructuring the use of existing resources.

6.0 RECOMMENDATIONS

After reviewing a report of this size, people are often concerned with the report's implications--where do we go from here? The answer is obviously not a simple one and can only be resolved through careful discussion and deliberation among Council members. This report represents a unique opportunity to examine a network of early intervention programs. The following recommendations are made in the hope of offering a contribution to future deliberations regarding the strengthening of early intervention programs in New Jersey.

6.1 Administrative Recommendations

- Greater collaboration needs to be instituted among state agencies that have a present and future role in early intervention program development. For example, a committee of representatives from Special Child Health Services, the Division of Mental Retardation, and the Department of Education should review their own monitoring of programs and discuss new legislative initiatives.
- When recommendations for new Council members are made, a program administrator from an early intervention program should be among those considered for appointment.
- Strategies need to be developed and implemented for improving professional and public awareness of early intervention programs. For example, a listing of all early intervention programs could be distributed to as many pediatricians and home visiting nursing programs as possible throughout the state. Mailings sent to parents regarding the Department of Health's registry of infants with developmental disabilities should also contain this listing.

6.2 Programmatic Recommendations

- Standards need to be developed for all phases of program operations. For example, consistent record-keeping procedures should be instituted for individual habilitation plans.
- Alternative strategies in the structure of programs need to be explored to deal with persistent programmatic weaknesses. For example, weekend or nighttime sessions might encourage participation of fathers. Parents with a high level of involvement could be paired with parents who need to increase their participation, thereby providing a more concentrated and personalized support system. In general, programs should approach these and other problems with the attitude that many problems can be solved without the addition of more funds.
- In order to reach more children needing early intervention services, new outreach efforts need to be considered. To increase participation, mobile vans might be employed in rural areas. Also, outreach and training with day care and Head Start centers might help to identify children whose developmental difficulties are not as apparent.
- Programs need to provide increased incentives for maximizing parent involvement. As one parent suggested, parents could rotate as baby-sitters during non-program hours. Arrangements such as these might help give parents time off for themselves and thus not utilize the program for this understandable purpose.

6.3 Additional Research Needed

- There is a need for the development of a model for program evaluation that can be readily used by every early intervention program. With a common methodology for data collection, such questions as the following might be addressed:
  - Does more intervention (e.g., longer and/or more frequent sessions) produce greater developmental changes in children?

- How do the effects of a transdisciplinary approach in staffing compare with those produced by an interdisciplinary approach?
- What are the longitudinal effects of early intervention with children of varying functional capabilities?

- The progression of change in parental attitude needs to be explored, by means of an instrument that can be administered on some regular basis to parents. Additional research is needed to examine the hypothesis that change in parental attitude influences a child's progress.
- Research is needed in the area of parent participation, to determine which forms of parent participation are most influential in predicting various outcomes of program interventions.
- Little is known about the program from a cost-benefit point of view. Research needs to be done to determine costs per unit of service.

APPENDIX A

PROGRAM ADMINISTRATOR SURVEY

Appendix A

Program Administrator Survey Date _____

Name_____ Position_____

Degree & Certification _____

Name of Program_____ Phone_____

Program Address _____ City _____ Zip _____

County Where Program is Located _____ Date When Program Began _____

****

A) FAMILY BACKGROUND — Write in the **actual number** of children in each category

1. **Ethnic Composition of Infants in Your Program**

Caucasian	Negro	American Indian	Asian	Hispanic	Other	Total Number in Your Program

2. **Home Environment of Infants in Your Program**
   - a. number living with both parents _____
   - b. number living with one parent _____
   - c. number living with relatives, but not parents _____
   - d. number living in other residences _____
   - e. other _____

3. **Presence of Siblings at Home**
   - a. number that have one or more siblings _____
   - b. number that have no siblings _____

B) FUNDING SOURCES — Write in the percentage of your total income in each category. This breakdown should total 100%.

1. % of Income	Funding Source
a. _____	Crippled Children Program (Special Child Health Services)
b. _____	Div. of Mental Retardation/Developmental Disabilities Council
c. _____	Div. of Special Education & Pupil Personnel Services
d. _____	SSI: Disabled Children's Unit
e. _____	Title XX
f. _____	Charities/Clubs (donations)
g. _____	Fees
h. _____	Town or County Government
i. _____	Other (please specify) _____

100% (your figures should total 100%)

2. Have you **attempted** (successfully or unsuccessfully) to collect third party payments for your services (i.e., insurance claims or medicaid)? _____yes _____no If your answer was "yes", please describe your experiences in trying to collect the payments. Please be specific - use the back side if needed.

_____

_____

_____

C) PUBLICIZING YOUR PROGRAM

Circle the number which best represents your level of activity in each of these areas. This would include whether you initiated or responded to contacts from others. If you would like to explain any of your responses, please do so on the back of this page.

--use this key for your responses--
--circle any one of the 5 numbers--

1 = never (have never attempted this at all)
2 = rarely (have tried this once or twice this year)
3 = sometimes (have tried this about 3-4 times this year)
4 = often (do this almost every month)
5 = constantly (do this a number of times a month)

	never	rarely	sometimes	often	constantly
1. mass media (TV, radio, newspaper)	1	2	3	4	5
2. contacts with doctors in private practice	1	2	3	4	5
3. contacts with local hospitals	1	2	3	4	5
4. distribution of brochures/program descriptions to parents and people visiting your program	1	2	3	4	5
5. distribution of brochures/program descriptions in locations outside your center (libraries, etc.)	1	2	3	4	5
6. contacts with pre-natal or genetic counseling centers	1	2	3	4	5
7. talks to community groups (PTA, Elks, etc.)	1	2	3	4	5
8. contacts with community or county agencies who might be referral sources to your program	1	2	3	4	5
9. other (please describe) _____	1	2	3	4	5

D) SERVICE CAPACITY

1. Total number of infants in your program _____
2. Indicate the number of children living in various counties who use your program.

Name of County	**Number of Children**
_____	_____
_____	_____
_____	_____
_____	_____

3. Age breakdown:
   a. less than 6 months old _____
   b. 6 months to less than 1 year old _____
   c. 1 year to less than 2 years _____
   d. 2 years to 3 years old _____

4. How many clients could you handle given your present resources? _____

5. What is the average number on your waiting list? _____

6. What is the average waiting time on this list? _____

7. To what degree is your program serving the number of infants needing services in your area?

we're not meeting the need at all	**we're somewhat meeting the need**	**we're definitely meeting the need**
1	2	3

What are your reasons for this judgement? _____

_____

_____

_____

E) STAFFING

Please describe each person associated with your program.

These three columns should add up to the total hours per week

Position	Degree & Certification	Total Hours per week	Hrs. per Week Providing Direct Services to Infants	Hrs. per Week Providing Direct Services to Parents	Hrs. per Week **not** Providing Direct Services, but Helping Out in Other Ways Like Consulting with Staff

F) PROGRAM EMPHASIS

Programs can have different emphases when working with the infants and thereby offer services which focus on certain areas more than others. Please indicate how you would describe your program's particular emphases by ranking these activity areas. In the lines below, put a "1" for the area which you emphasize the most, a "2" for the area which you next most emphasize, a "3" for the one you emphasize the most after that, and so on until you have ranked all 8 areas.

1. a.____activities dealing with expressive language skills
   b.____activities dealing with receptive language skills
   c.____activities dealing with toileting skills
   d.____activities dealing with feeding skills
   e.____activities dealing with gross motor skills
   f.____activities dealing with fine motor skills
   g.____activities dealing with cognitive development skills
   h.____activities dealing with social development skills

2. Whether parents and staff work together and how they interact can vary in many different ways. Also, we know that the structure of a program session can change during any particular day, but we'd like to know what happens **most of the time.** Please rank the following by putting a "1" for the type of parent/staff interaction which happens **most** often, a "2" for the type which happens the next most often, a "3" for the one which happens most often after that, etc. Please rank **all** 4.

   ____a. Staff members do activities with the child while the parents watch what they are doing
   ____b. Parents do activities with the child while staff members watch what she/he is doing
   ____c. Both parents and staff members do activities with the child at the same time
   ____d. Staff members do activities with the child while parents are somewhere else

G) TRANSPORTATION ISSUES

1. Have you experienced any transportation difficulties? _____yes _____no

If you answered yes to the previous question, please answer the following:

2. Describe your **most serious** transportation difficulty _____

3. Describe your **next most serious** transportation difficulty _____

4. Describe any other transportation difficulties which you think are important, but less serious than the previous two _____

H) EVALUATION PROCESSES

1. What are your intake procedures? _____

2. What formal evaluation of children takes place in your program? (Include names of instruments/forms, if used, how often this takes place, and who participates in the evaluation)

3. How frequently do you review the goals and objectives for each child and subsequently make revisions in them when needed?

   a. ____at least once a month
   b. ____six times a year
   c. ____four times a year
   d. ____two times a year
   e. ____once a year
   f. ____we don't re-evaluate the goals & objectives
   g. ____we don't have written goals & objectives

4. Check which one **best** describes the extent to which parents participate in reviewing the goals and objectives for their child. **Check only one.**

   ____a. Parents and staff discuss how well the child is achieving the objectives. Then the new or revised objectives are written by parents and staff together.

   ____b. Parents and staff discuss how well the child is achieving the objectives. Then, the staff writes new objectives without the parent being present.

   ____c. Staff reviews how well the child is achieving the objectives, writes new or revised objectives, and later discusses the changes with the parents.

   ____d. Staff reviews how well the child is achieving the objectives. Then the staff writes new or revised objectives, but does not share them with parents.

   ____e. Other (describe).

5. How willing are parents to discuss with staff the goals and objectives for their child?

not very willing	slightly willing	moderately willing	very willing	doesn't apply
1	2	3	4	5

I) **GAPS IN SERVICES**

Please describe what you consider to be the most important gaps in the services you offer as well as what prevents you from filling in those gaps at the present time.

J) **PARENT PARTICIPATION**

We are trying to find out what kinds of parent involvement exist in your program and how much you emphasize each one. **Please circle "yes" or "no"** for each item listed. **If you circled "yes" circle any one of the 4 numbers to the right** to indicate how much you emphasize this.

Does this form of parent involvement exist in the program?			**If yes, how much do you emphasize this?**			
			exists, but is not emphasized much	exists and is slightly emphasized	exists and is moderately emphasized	exists and is strongly emphasized
a. meetings or discussions with treatment staff to share information about the child	no	yes	1	2	3	4
b. parent discussion groups	no	yes	1	2	3	4
c. Individual counseling with a social worker or psychologist	no	yes	1	2	3	4
d. participation in the child's treatment at the center	no	yes	1	2	3	4
e. home visits by staff from the program	no	yes	1	2	3	4
f. a parent organization	no	yes	1	2	3	4
g. fundraising activities	no	yes	1	2	3	4
h. outreach to community individuals	no	yes	1	2	3	4
i. Family Days or Nights	no	yes	1	2	3	4
j. other (specify)_____	no	yes	1	2	3	4

K) TARGET POPULATION

We are interested in knowing about the functional limitations of children in your program. We would like your views of the children at two points in time--what they are like today and what you predict they will be like when they are 3 years old and are ready to leave your program. You will find a number of quick Functional Assessment Forms enclosed. Please fill out one form for each child who has been in the program for at least 2 months.

You might well recognize items on the form as it is an adaptation of the Denver Developmental Screening Test. We are aiming to have forms filled out on every child. Please be sure to include the parent's code number for the child you are describing plus his/her primary categorical diagnosis (e.g., Cerebral Palsy, etc.). If you are not able to fill out a form on every child, please call Danny Goldberg at the Developmental Disabilities Technical Resource Center as soon as possible to work out alternative arrangements (212/867-8630).

APPENDIX B

PARENT QUESTIONNAIRE

Developmental Disabilities Training Systems and Technical Resource Center - Region II

Welfare Research, Inc. 99 Park Avenue New York, N.Y. 10016 (212) 867-8635

Virginia Hayes Sibbison, PhD
Executive Director
Welfare Research, Incorporated

August, 1979

Dear Parent:

The New Jersey Developmental Disabilities Council is beginning an extremely important project and would appreciate your help as a parent. As you know, the Council plans and promotes services for developmentally disabled individuals and makes recommendations to the State government on the improvement of existing services. In the past, the Council has supported children's programs like the early intervention/child development program in which your child participates. The Council is now in the process of examining the strengths and weaknesses of programs to plan for more effective services to your children. The Council is therefore sponsoring a statewide survey of all parents who have children in early intervention/child development programs and your views are an important source of information. We assure you that your responses will not be shown to any of the staff in your child's program or to any members of the Council.

The Developmental Disabilities Technical Resource Center is working with the NJ Developmental Disabilities Council to conduct this survey. A questionnaire has been enclosed for the mother or primary caretaker to fill out. The questionnaire might appear to be long, but we hope you will take the time to respond. We know you are concerned about your child's development and we expect the survey will help to benefit your child's program as well as those programs needed by other children throughout the State.

It would be helpful if you are as accurate as possible in your responses. The usefulness of the study depends on your openness to areas of both satisfaction and dissatisfaction with your child's program. Again, your responses will not be shown to any program staff. Also, we are using code numbers and are not asking for your name. In fact, the program administrator of your child's program addressed your envelope to assure confidentiality.

On behalf of the Council, I genuinely thank you for your time in filling out the questionnaire. With almost 700 questionnaires being sent out, we are shooting for 100% participation. Please return the questionnaire within the next week in the envelope provided. If you have any concerns or questions about the survey, please feel free to call me at 212/867-8630.

Sincerely,

Daniel C. Goldberg
Research Evaluation Specialist

Parent Questionnaire

Code Number _____ Today's Date _____

Town where you live _____ County where you live _____

Name of the program attended by your child _____

How many miles from the program do you live? _____ Do both parents live at home? _____ yes _____ no

Number of brothers or sisters, if any, living at home _____ Date when your child began the program _____

****

1. **How old was your child when:**

   a. you first noticed that your child had or might have a special problem or difficulty ____ years ____ months

   b. you were told by a doctor or other professional that your child has or might have a special problem ____ years ____ months

   c. you first learned about this program ____ years ____ months

   d. your child started participating in the program ____ years ____ months

2. **How did you find out about the program**? (check one)

   ____a. home visiting nurse
   ____b. doctor
   ____c. friend or relative
   ____d. hospital staff
   ____e. hospital social services person
   ____f. health clinic or similar agency
   ____g. voluntary developmental disabilities organization like UCP or ARC
   ____h. person who has a child in the program
   ____i. media (TV, radio, brochure or poster, newspaper)
   ____j. other (please specify)

3. **We are trying to find out what type of assistance your child is receiving in the program and how helpful it has been. Please circle "yes" or "no" for each item listed. If you circled "yes", circle any one of the 4 numbers to the right to indicate how helpful this has been to you.**

Is your child receiving assistance with:			**If yes, how helpful has this been?**			
			not very helpful	slightly helpful	moderately helpful	very helpful
understanding what is said to him/her?	no	yes	1	2	3	4
expressing himself through words?	no	yes	1	2	3	4
toileting skills?	no	yes	1	2	3	4
feeding skills	no	yes	1	2	3	4
physical skills like walking or sitting?	no	yes	1	2	3	4
hand coordination skills like holding a glass or picking up a toy?	no	yes	1	2	3	4
cognitive skills like recognizing objects in pictures?	no	yes	1	2	3	4
social skills like playing a game with other children?	no	yes	1	2	3	4

4. **We are also trying to find out what kinds of parent involvement exist in your program and how helpful they have been. Please circle "yes" or "no" for each item listed. If you circled "yes", circle any one of the 4 numbers to the right to indicate how helpful this has been to you.**

Does this form of parent involvement exist in the program?			**If yes, how helpful has this been?**			
			not very helpful	slightly helpful	moderately helpful	very helpful
understanding what is said to him/her?	no	yes	1	2	3	4
meetings and discussions with the treatment staff to share information about your child	no	yes	1	2	3	4
parent discussion groups	no	yes	1	2	3	4
individual counseling with a social worker or psychologist	no	yes	1	2	3	4
participation in your child's treatment at the center	no	yes	1	2	3	4
home visits by staff from the program	no	yes	1	2	3	4
a parent organization	no	yes	1	2	3	4
fund raising activities	no	yes	1	2	3	4
outreach to community groups or individuals	no	yes	1	2	3	4
Family Days or Family Nights	no	yes	1	2	3	4

We are interested in knowing how helpful you find different parts of the program. Please circle any one of the numbers in the questions below. You will notice that some of the numbers are reversed in certain questions. This is done to aid careful consideration of each question.

5. Having a special child often places extra demands on a family. We'd like to know how helpful the program is in assisting you with various aspects of your family life.

   a. **How helpful is the program in assisting you with the impact of having a developmentally disabled child?**

not very helpful	slightly helpful	moderately helpful	very helpful
1	2	3	4

   b. **How helpful is the program with issues between you and your spouse?**

doesn't apply	very helpful	moderately helpful	slightly helpful	not very helpful
5	4	3	2	1

   c. **How helpful is the program to you in assisting your other child(ren) to cope with having a developmentally disabled brother or sister?**

doesn't apply	very helpful	moderately helpful	slightly helpful	not very helpful
5	4	3	2	1

   d. **How helpful is the program with difficulties concerning other family members** (your parents, in-laws, grandparents, etc.)?

not very helpful	slightly helpful	moderately helpful	very helpful	doesn't apply
1	2	3	4	5

6. **How often do staff members give you information about your child?**

hardly ever	sometimes	often	almost always
1	2	3	4

a. **How understandable is this information given to you by staff?**

not very understandable	slightly understandable	moderately understandable	very understandable
1	2	3	4

b. **How often does the information include the specifics that you want?**

hardly ever	sometimes	often	almost always
1	2	3	4

c. **How willing are staff members to discuss with you the goals and objectives for your child?**

doesn't apply	very willing	moderately willing	slightly willing	not very willing
5	4	3	2	1

7. **The length of each program is ...**

too short	just about right	too long
1	2	3

8. **The number of times a week your child is involved in the program is...**

not enough times	just about right	too many times
1	2	3

9. **The following questions relate to the help you receive from the program in learning new ways of dealing with your child at home.**

a. **How helpful is the program in assisting you to play with your child at home?**

not very helpful	slightly helpful	moderately helpful	very helpful
1	2	3	4

b. **How helpful is the program in assisting you to do physical/speech therapy or other treatment exercises at home?**

very helpful	moderately helpful	slightly helpful	not very helpful
4	3	2	1

c. **How helpful is the program in assisting you with the day to day care of your child at home (feeding, toileting, etc.)?**

doesn't apply	very helpful	moderately helpful	slightly helpful	not very helpful
5	4	3	2	1

d. **How helpful is the program in improving your understanding of child development and behavior problems (crying, temper tantrums, etc.)?**

not very helpful	**slightly helpful**	**moderately helpful**	**very helpful**	**doesn't apply**
1	**2**	**3**	**4**	**5**

10. **Whether parents and staff work together and how they interact can vary in many different ways. Also, we know that the structure of a program session can change during any particular day, but we'd like to know what happens most of the time. Please rank the following by putting a "1" for the type of parent/staff interaction which happens most often, a "2" for the type which happens the next most often, a "3" for the one which happens most often after that, etc. Please rank all 4.**

____a. Staff members do activities with the child while the parents watch what they are doing
____b. Parents do activities with the child while staff watch what she/he is doing
____c. Both parents and staff members do activities with the child at the same time
____d. Staff members do activities with the child while parents are somewhere else

11. **We would like to ask the same question, but this time we would like to know what you would ideally prefer. Again, put a "1" for the item which you would ideally most like to happen, a "2" for the one which you would next most prefer, and so on until you have ranked all 4 items.**

____a. Staff members do activities with the child while the parents watch what they are doing
____b. Parents do activities with the child while staff watch what she/he is doing
____c. Both parents and staff members do activities with the child at the same time
____d. Staff members do activities with the child while parents are somewhere else

12. **We are interested in knowing more about which parts of the program you find most helpful. Please rank the following parts of the program by putting a "1" on the line for the program area you find most** helpful, a "2" for the area you find **next most** helpful, a "3" for the area you think is most helpful after that, and so on. **Please rank all 5 areas.**

Rank (1 through 5) **Program Area**

____ helping you learn to do activities at home with your child

____ helping you cope with the impact of having a developmentally disabled child

____ helping you learn to better manage the physical needs of your child at home in such areas as feeding, toileting, and bathing

____ giving you information that is understandable and in the amount of detail you want

____ helping you deal with family life issues

13. **What is the best aspect of the program?** _____

_____

14. **What is the worst aspect of the program?** _____

_____

15. **What would you like to see changed or added to the program?** _____

_____

_____

16. **What, if any, of the following services do you think your child will need 5-10 years from now? Check as many as apply.**

____special residential school
____special classes
____special living arrangements outside the home
____physical/occupational therapy
____special transportation arrangement
____speech therapy
____psychological counseling or guidance
____special recreational or leisure time activity programs
____health/medical services
____pre-vocational training
____other (describe) _____
____my child will not need any of these services
____I don't know what my child will need at that time

17. **We would like to know some brief information about your family's background.**

Information about Mother	Information about Father
Age _____ **Highest grade completed in school:** ____less than 7 years of school ____junior high school ____some high school, but did not finish ____12th grade (high school diploma) ____some college, but did not finish ____college degree ____graduate or professional school completed **What kind of work do you do?** (please be specific, for example: real estate broker, self-employed) _____	Age _____ **Highest grade completed in school:** ____less than 7 years of school ____junior high school ____some high school, but did not finish ____12th grade (high school diploma) ____some college, but did not finish ____college degree ____graduate or professional school completed **What kind of work do you do?** (please be specific, for example: real estate broker, self-employed)

Total Family Income (check one)

____on some form of public assistance	____17,000 to 22,999
____less than 5,000	____23,000 to 28,999
____5,000 to 10,999	____29,000 to 34,999
____11,000 to 16,999	____35,000 and above

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18. **We are interested in knowing your views of what your child is able to do. We would like to know what he/she can do now and what you predict he/she will be able to do at the age of 3 when most children leave the program. Please put a check mark for each of the 40 skill areas--make sure you put a check mark in both the "present" and "future" columns.**

	TODAY			WHEN 3 YEARS OLD		
GROSS MOTOR SKILLS	can do it	can't do it	don't know	will do it	won't do it	don't know
1. While lying on stomach and using arms as support, child lifts head and chest up						
2. Child rolls from back to stomach or from stomach to back						
3. Child sits without support after you place him/her in a sitting position.						
4. Child pulls self to standing position while holding onto solid object						
5. Child gets self to sitting position						
6. Child walks around furniture while holding onto it						
7. Child walks with good balance and rarely falls						
8. Child walks up steps holding on to rail or wall, but not to a person						
9. Child throws a ball overhand						
10. Child jumps in place						
FINE MOTOR-ADAPTIVE SKILLS						
11. While lying on back, child touches hands together in the middle of his/her body						
12. While lying on back, child uses eyes & head to follow an object moving from left to right						
13. Child grasps a rattle for a few seconds when given to him/her						
14. While sitting on parent's lap, child reaches for an object within reach on a table						
15. Child transfers a block from one hand to the other hand						
16. Child picks up small object with thumb and index finger						
17. Without being instructed, child gets at objects in a container by dumping them out						
18. Child stacks four blocks on top of each other making a tower						
19. When being shown how to do it, child imitates drawing a vertical line						
20. After being shown a circle, child copies the circle						
LANGUAGE SKILLS						
21. Child laughs aloud						
22. Child turns to the direction of your voice when he/she cannot see you						
23. Child imitates speech sounds which you make						

	TODAY			WHEN 3 YEARS OLD		
	can do it	can't do it	don't know	will do it	won't do it	don't know
24. Child says "Dada" or "Mama" specifically to his/her mother or father						
25. Child says a phrase using two words like "want milk" or "play ball"						
26. When parent asks child to point to a specific part of his/her body, child does this						
27. Child follows most short directions like "Give the block to Mommy"						
28. When showing child simple pictures like one of a dog, child names at least 1 of them						
29. Child gives first and last name when asked						
30. Child recognizes colors like when asked for a red block, child gives you the right one						

PERSONAL-SOCIAL SKILLS

31. Without touching or speaking to child, he/she smiles spontaneously						
32. Child feeds self a cracker or cookie						
33. Child tries to get at a toy which is a little out of his/her reach						
34. Child holds a cup and drinks from it without much spilling						
35. Child lets you know he/she wants something with gestures or words, but not by crying						
36. Child uses a spoon or fork and doesn't spill much						
37. Child removes parts of his/her clothing like jacket or shoes						
38. Child plays games with other children like building a sand castle together or tag						
39. Child does not get to upset when the mother is not around or leaves the room						
40. Child can put on and take off clothes without too much help from the mother						

APPENDIX C
FUNCTIONAL ASSESSMENT FORM

Appendix C

FUNCTIONAL ASSESSMENT FORM

Parent Code Number _____ Center _____

Child's Categorical Diagnosis _____

	TODAY			WHEN 3 YEARS OLD		
GROSS MOTOR SKILLS	can do it	can't do it	don't know	will do it	won't do it	don't know
1. While lying on stomach and using arms as support, child lifts head and chest up						
2. Child rolls from back to stomach or from stomach to back						
3. Child sits without support after you place him/her in a sitting position.						
4. Child pulls self to standing position while holding onto solid object						
5. Child gets self to sitting position						
6. Child walks aroung furniture while holding onto it						
7. Child walks with good balance and rarely falls						
8. Child walks up steps holding on to rail or wall, but not to a person						
9. Child throws a ball overhand						
10. Child jumps in place						
FINE MOTOR-ADAPTIVE SKILLS						
11. While lying on back, child touches hands together in the middle of his/her body						
12. While lying on back, child uses eyes & head to follow an object moving from left to right						
13. Child grasps a rattle for a few seconds when given to him/her						
14. While sitting on parent's lap, child reaches for an object within reach on a table						
15. Child transfers a block from one hand to the other hand						
16. Child picks up small object with thumb and index finger						
17. Without being instructed, child gets at objects in a container by dumping them out						
18. Child stacks four blocks on top of each other making a tower						
19. When being shown how to do it, child imitates drawing a vertical line						
20. After being shown a circle, child copies the circle						

LANGUAGE SKILLS	TODAY			WHEN 3 YEARS OLD		
	can do it	can't do it	don't know	will do it	won't do it	don't know
21. Child laughs aloud						
22. Child turns to the direction of your voice when he/she cannot see you						
23. Child imitates speech sounds which you make						
24. Child says "Dada" or "Mama" specifically to his/her mother or father						
25. Child says a phrase using two words like "want milk" or "play ball"						
26. When parent asks child to point to a specific part of his/her body, child does this						
27. Child follows most short directions like "Give the block to Mommy"						
28. When showing child simple pictures like one of a dog, child names at least 1 of them						
29. Child gives first and last name when asked						

PERSONAL-SOCIAL SKILLS						
30. Child recognizes colors like when asked for a red block, child gives you the right one						
31. Without touching or speaking to child, he/she smiles spontaneously						
32. Child feeds self a cracker or cookie						
33. Child tries to get at a toy which is a little out of his/her reach						
34. Child holds a cup and drinks from it without much spilling						
35. Child lets you know he/she wants something with gestures or words, but not by crying						
36. Child uses a spoon or fork and doesn't spill much						
37. Child removes parts of his/her clothing like jacket or shoes						
38. Child plays games with other children like building a sand castle together or tag						
39. Child does not get to upset when the mother is not around or leaves the room						
40. Child can put on and take off clothes without too much help from the mother						

APPENDIX D
GROUP INTERVIEW PROTOCOL-PARENTS AND STAFF

Appendix D

Group Interview Protocol - Parents and Staff

1. Tell me about your program - how it operates, how often, etc.

2. I would like to know about what it was like when you (parents) first met with staff when you were enrolling your child.
   a. What did staff tell you about what you could expect the program would accomplish for your child?
   b. To what degree did you become more optimistic or pessimistic based on what staff told you?

3. What specific results have been accomplished to date due to the program's interventions? Please feel free to include results which might not focus on your child per se. Also, I am **not** referring to goals or hopes, but to actual concrete accomplishments.

4. What are the most positive aspects of your program?

5. What are the things that you are not pleased with?

6. What specific impairments or changes would you like to see made in the program?

7. Are there any other concerns you'd like to express that haven't been covered yet?

APPENDIX E
MONITORING AND EVALUATION PROCEDURES

Appendix E

Monitoring and Evaluation Procedures Center _____

When calling, provide a definition of "formal" and "informal" procedures by stating the following:

a. **formal**-written procedures or happens on a scheduled, routine basis
b. **informal**-unwritten procedures or happens when needed or when the opportunity arises

Circle One	
Y N	1. Does your infant program have a written statement regarding its philosophy and purpose?
Y N	2. Does your infant program have a written statement of goals & objectives?
Y N	3. Does the infant program have a written evaluation plan?
I F N I F N Y N Y N	4. Which of the following assessment methods do you use a. informal or formal staff evaluation b. informal or formal review of overall service c. staff evaluation instruments d. informal or formal feedback from parents e. other _____
Y N	5. Is the infant program licensed by any local, federal, or state agency? If yes, what agency? _____
Y N	6. Do you have a governing board?
Y N	7. Do you have a policies and procedures manual for staff?
Y N	8. Does any person(s) external to the infant program conduct either informal or formal evaluations of your program?

Y N	9. Do you have an IHP (i.e., an individual plan) for each child? Does it include:
Y N	a. age
Y N	b. sex
Y N	c. ethnic background
Y N	d. income range
Y N	e. address
Y N	f. developmental level or behavioral assessment
y n	- standardized test
y n	- own instrument
Y N	g. primary functional limitation
Y N	h. type & severity of disability, if established
Y N	i. goals and objectives
Y N	j. documentation of parent participation in IHP development
Y N	k. medical information
Y N	l. notes on parent conferences or meetings
I F N	10. Do you conduct informal or formal periodic review of the IHP for each child?
Y N	11. Is a written goals/objectives sheet for a child given to parents?
Y N	12. Are written attendance records kept for children?
Y N	13. Are written attendance records kept for each parent?
Y N	14. Do you conduct any data analysis on child or parent change?

APPENDIX F

SCORING PROCEDURES FOR FUNCTIONAL ASSESSMENT FORM

Appendix F

Methods Used for Scoring the Functional Assessment Form*

A score was obtained for each of the four areas of the FAF. The scores represent the developmental age level that the child is currently functioning at in each of the areas. The score in each area is obtained as follows:

a) Find the highest Pass.

b) Find the 50% age level for that P from the chart in the back of the Denver. Use sample norms for total population, not the separate ones for boys and girls. Use the exact decimal score -- do not round off.

c) That 50% age level of the highest Pass will be the score **unless** there are two or more Failures on items which fall completely below the **50% age level of the highest Pass**. Disregard "don't know" when scoring; that is they do not count as Failures.

d) If there are two or more Failures below the 50% age level of the highest Pass, then find the next highest pass and repeat same procedure.

---

* Developed by Meisel, J. **Evaluation Report: A Nationally Organized Project to Provide Comprehensive Services for Atypical Infants and their Families.** New York. United Cerebral Palsy Associations, Inc., 1976.

APPENDIX G

50% AGE NORMS USED TO CALCULATE DEVELOPMENTAL QUOTIENTS

Appendix G

50% Age Norms Used to Calculate Developmental Quotients

	50% Age Norms
1. While lying on stomach and using arms as support, child lifts head and chest up	3.0
2. Child rolls from back to stomach or from stomach to back	2.8
3. Child sits without support after you place him/her in a sitting position.	5.5
4. Child pulls self to standing position while holding onto solid object	5.8
5. Child gets self to sitting position	7.6
6. Child walks around furniture while holding onto it	9.2
7. Child walks with good balance and rarely falls	12.1
8. Child walks up steps holding on to rail or wall, but not to a person	17.0
9. Child throws a ball overhand	19.8
10. Child jumps in place	22.3
11. While lying on back, child touches hands together in the middle of his/her body	2.2
12. While lying on back, child uses eyes & head to follow an object moving from left to right	2.4
13. Child grasps a rattle for a few seconds when given to him/her	3.3
14. While sitting on parent's lap, child reaches for an object within reach on a table	3.6
15. Child transfers a block from one hand to the other hand	5.6
16. Child picks up small object with thumb and index finger	10.7
17. Without being instructed, child gets at objects in a container by dumping them out	13.4
18. Child stacks four blocks on top of each other making a tower	17.9

	50% Age Norms
19. When being shown how to do it, child imitates drawing a vertical line	21.7
20. After being shown a circle, child copies the circle	31.2
21. Child laughs aloud	2.0
22. Child turns to the direction of your voice when he/she cannot see you	5.6
23. Child imitates speech sounds which you make	7.0
24. Child says "Dada" or "Mama" specifically to his/her mother or father	10.1
25. Child says a phrase using two words like "want milk" or "play ball"	19.6
26. When parent asks child to point to a specific part of his/her body, child does this	17.0
27. Child follows most short directions like "Give the block to Mommy"	19.8
28. When showing child simple pictures like one of a dog, child names at least 1 of them	20.3
29. Child gives first and last name when asked	32.0
30. Child recognizes colors like when asked for a red block, child gives you the right one	36.0
31. Without touching or speaking to child, he/she smiles spontaneously	1.9
32. Child feeds self a cracker or cookie	5.3
33. Child tries to get at a toy which is a little out of his/her reach	5.8
34. Child holds a cup and drinks from it without much spilling	11.7
35. Child lets you know he/she wants something with gestures or words, but not by crying	12.2
36. Child uses a spoon or fork and doesn't spill much	14.4
37. Child removes parts of his/her clothing like jacket or shoes	15.8
38. Child plays games with other children like building a sand castle together or tag	24.0
39. Child does not get too upset when the mother is not around or leaves the room	36.0
40. Child can put on and take off clothes without too much help from the mother	43.2

APPENDIX H

PARENT COMMENTS ABOUT POSITIVE PROGRAM ASPECTS

Appendix H

Interviews

Positive Aspects - Parents

1) There was little waiting to start the program.

2) Transportation is provided.

3) Parents get a break from their child.

4) A home-type atmosphere exists at the center.

5) Staff demonstrate much patience/flexibility/caring/persistence; this leads to higher parent motivation.

6) Program is individualized to the particular needs of each child.

7) Discipline at home is fostered by the model provided by staff.

8) There are many different therapists right at the center.

9) Meetings for mothers - help parents learn from others and share ideas.

10) A bulletin board exists for other resources.

11) The social worker helps with laws, information, etc.

12) The evaluation of children demonstrated that staff knew a great deal.

13) Through the group experience, children learn patience, socialization skills, etc.

14) Teachers talk to doctors to coordinate child's treatment.

15) Parents do exercises with the therapists and actually try them out.

16) Siblings come in the summer.

17) Staff give parents referrals to understanding doctors.

18) Staff check into placements for pre-school.

19) Home visits allow the child to be seen at home.

20) Staff help with **all** types of problems (including marital difficulties) and at all times of day.

21) Program focuses on home skills.

22) Parents can borrow equipment to use at home.

23) Volunteers provide additional assistance at the center.

24) The mere existence of program provides hope and support.

25) There is a sliding scale for payment of fees.

26) Staff rely on different tests (5-7) for evaluation.

27) Parents see improvements in other children - lends encouragement when things are slow/not improving in their own child.

APPENDIX I

PARENT COMMENTS ABOUT NEEDED PROGRAM IMPROVEMENTS

Appendix I

Improvements - Parents

1) Stop changing staff so much - if staff member leaves, replace him/her immediately. Also, the number of staff can change from day to day.

2) Have parents be "den mother" for unstructured play at different times in day.

3) Staff need to keep parents more informed of child's progress and do this at a convenient time.

4) Have more sessions if development is not improving.

5) See the child more at start of program.

6) Have more therapy and longer sessions on additional days in week; another option would be to conduct shorter sessions.

7) Head therapists should see each child, at least to watch the work being done by others.

8) Transportation is needed.

9) Program begins too late (11:15 a.m.).

10) A baby sitting service is needed.

11) Psychologist should be hired to help with personal problems.

12) Program should operate during summers as well.

13) More home visits are needed (not just once or twice a year).

14) Separate old and new parents - group parents specific to the child's problem.

15) Therapists need to spend more time with each baby because, as a parent, "I can't do it right".

16) Program needs to be more individualized, varied, and more challenging to the child.

17) Staff need more feedback from parents.

18) Too long a wait exists at the beginning; there should be no waiting list.

19) Program needs to involve more of the family so others know what to do.

20) Program needs equipment for parents to use at home.

21) A bigger classroom should be found; it is too crowded.

22) Another teacher or therapist is needed.

23) Hold evening sessions for husbands; a group for fathers is needed.

24) More depth to mother's group is needed; they should have more structure and encourage people to talk.

25) More physical therapy should be given to child.

26) Administration needs to be more responsive to parent's needs.

27) Have no more than 3-4 children at a program session.

28) Staff need to focus more on quality of behavior changes in child, not quantity.

29) Have more speakers at parent meetings.

APPENDIX J

STAFF COMMENTS ABOUT POSITIVE PROGRAM ASPECTS

Appendix J

Positive Aspects - Staff

1) Staff use much teamwork and support one another.

2) Staff are highly competent.

3) Therapy is done right in the group, not at another office.

4) Transportation is provided.

5) Home training focus integrates suggestions into everyday life with parent's **own** resources.

6) Home visits are conducted and allow staff to see child more as a whole; parents can be more open at home; self care skills are easier to cover at home.

7) Interdisciplinary approach is offered here.

8) Individual time is spent with child.

9) Parents are here; this helps develop informal contacts, a support system, and friends.

10) Grouping of children is planned - for example, ambulatory vs. more physically involved.

11) Program offers social service - books, referrals, training in their rights.

12) Program is flexible adjusting to the child or parent's needs.

13) Program has a toy lending library.

14) Gym is used for gross motor skills.

15) Parent groups offer both knowledge and emotional support.

16) Program has a transdisciplinary approach to working with the child.

APPENDIX K

STAFF COMMENTS ABOUT NEEDED PROGRAM IMPROVEMENTS

Appendix K

Improvements - Staff

1) More referrals are needed; more public awareness would help this.
2) Have less staff turnover.
3) More family involvement (fathers, grandparents, etc.) would be helpful.
4) More resources like books and toys to lend to parents need to be acquired.
5) Have more social work as part of the program.
6) Hire a full time psychologist.
7) Salaries need to be raised; state support from year to year is uncertain.
8) Hire more male staff; this might promote father participation.
9) Transportation is needed.
10) Provide a baby sitting service for siblings at the center.
11) Staff need to be working full time, not part-time.
12) Have one person as primary case coordinator.
13) Home visiting program is needed.
14) Program needs facilities to make adaptive equipment for children.
15) Parent group needs a counselor.
16) Provide more/auxiliary therapy during week.
17) Larger space is needed.
18) Each program session needs to be longer.
19) Staff need more preparation and discussion time.
20) Pressure to produce a high enrollment of children should be decreased.

21) More specialized equipment is needed.

22) Create more public information materials, particularly for the Spanish community.

23) Program needs a greater link with intensive care units of hospitals.

24) Doctors need to be more informed of developmental disabilities and early intervention programs.

25) Eliminate waiting list with more resources.

26) Program needs to involve fathers more.

27) Provide more opportunities and time for staff development (conferences, courses, etc.).

28) Parents need to be more fully informed about the transdisciplinary approach.

29) State and/or county needs a resource center for program staff.

30) Staff need to be better trained in understanding and handling family dynamics.

31) More time needs to be given to staff supervision.

APPENDIX L

PARENT COMMENTS ABOUT RESULTS OF PROGRAM PARTICIPATION

Appendix L

Results - Parents

1) Parents more fully understand their child's condition and can see developmental milestones.

2) Parents have gained skills in working with their child at home, like doing speech therapy.

3) Parents have developed a positive attitude - they don't hide anymore and have greater acceptance; often this is due to program staff pointing out what the child **can** do.

4) Changes in children have taken place in such areas as feeding skills, physical development (e.g., less hypertonicity), social skills.

5) Siblings have greater understanding; they play with their disabled brother or sister more now.

6) Parents give more attention to siblings, now; they don't overfocus as much on the child with the developmental disability.

7) Parent's knowledge of community resources has increased.

8) Feelings of helplessness and impotence have lessened, often due to staff pointing out the child's progress.

9) Other family members, such as in-laws, now understand and interact more with the child.

10) Discipline at home has increased.

11) Community acceptance of children has improved; people "pity" parents less.

12) Parents have made new friends.

APPENDIX M

STAFF COMMENTS ABOUT RESULTS OF PROGRAM PARTICIPATION

Appendix M

Results - Staff

1) Program finds placements/referrals for parents.

2) Children develop a positive self-image by promoting successful growth; this stops the potential cycle of failure.

3) Children are primed for pre-school and future learning.

4) Children learn to get along in groups and social situations.

5) Families get connected to ancillary services-program is a broker.

6) Parents are more aware of their rights.

7) Parents get a break from their child and this tends to dampen anger.

8) More positive attitudes in parents are developed as seen in:
   a. heightened bonding
   b. more child holding
   c. increased normality of parent-child relationship (less "smothering" or leaving the child alone)

9) Parents are stronger emotionally from the relief that someone cares; programs are their only resource as doctors do not care.

10) Improvements have been made in pre-school programs; programs educate parents who in turn demand either better services or the creation of a program.

11) Community people and agencies are more aware of our existence.

12) Program helps achieve quality when developmental milestones are achieved.

13) With lower functioning children, program can be preventive in that it maintains skills; program helps children before poor habits set in and are difficult to change.

14) Social development in children is increased - less fears and temper tantrums from frustrations.

15) Parents become good observers and have new skills to help their child at home.

16) Low socioeconomic families are served.

17) Siblings get more attention by increasing overall parenting skills; program also shows siblings how they can help out.

18) Based on the model the program has provided, a church, housing one program, is developing a new group home.

19) New doctors are becoming more sensitive to children with developmental disabilities due to their visits during internship and residences.

20) Last year, the majority of children with mental retardation tested as "educable" as opposed to "trainable."

21) Pre-school teachers say they can tell which children went to early intervention programs and which did not.

22) Programs help reduce divorce among parents.

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